ANXIETY IN SIBLINGS OF CHILDREN WITH CANCER

by

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SUPERVISORY COMMITTEE APPROVAL

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FINAL READING APPROVAL

To the Graduate Council of The University of Utah:

I have read the thesis of Marcia L. Nobis in its final form and have found that (1) its format, citations, and bibliographic style are consistent and acceptable; (2) its illustrative materials including figures, tables, and charts are in place; and (3) the final manuscript is satisfactory to the Supervisory Committee and is ready for submission to the Graduate School.

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ABSTRACT

Although much research attention has been given to children with cancer and their parents, limited information is available regarding their siblings and the anxieties they may experience. The purpose of this study was to assess the anxieties that school-age siblings of children with cancer experience and explore the variables suspected to affect the amount and type of anxiety expressed.

Patterned after a study by Waechter (1968, 1970), two measures were utilized to assess anxiety. Sarason's General Anxiety Scale for Children was used to measure general anxiety and a modification of the Thematic Apperception Test was used to measure anxiety regarding body integrity.

Thirty-two healthy children between the ages of 6 and 10 years, whose sibling had been treated for cancer within the previous three years, and 28 healthy children, serving as a comparison group, were tested.

Results showed that as a group, siblings of children with cancer did not express greater anxiety than children of the comparison group. However, when these same siblings were grouped according to the patient's treatment status, significant differences were noted. Whereas siblings of children currently

receiving or having completed treatment did not express greater anxiety, those siblings of children who had died expressed significantly greater anxiety. Sex differences were also noted, with males whose sibling had died expressing significantly greater anxiety. Analyzing mother's perceptions of children's behavior changes as an indicator of children's anxiety revealed mild to moderate intermittent changes after diagnosis, but pronounced and sometimes persistent behavior changes after the death of the child.

These findings combined with future research with siblings could provide better understanding of anxieties and adaptation processes, and could assist health professionals to provide appropriate intervention and primary prevention for families adapting to life with a potentially life-threatening, potentially curable illness.

CONTENTS

LIST OF TABLES

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CHAPTER I

INTRODUCTION

A primary concern for nursing is to promote man's physiologic and psychosocial adaptation in both health and illness (Roy, 1973). Health has been defined as a dynamic state of adaptation to stresses or stimuli in the internal and external environment (Dubos, 1959; King, 1971). Stresses of the internal and external environment are ever changing and thus require ongoing adaptation for maintenance of health.

Anxiety, regardless of its source, acts as a profound stress requiring adaptation of the individual experiencing anxiety. Illness creates anxiety. When the illness is cancer, the anxiety intensifies immeasurably.

The very word "cancer" creates painful images of a slow, pitiful death and strikes fear in the heart of every person. When one hears of cancer in a child the image becomes almost unbearable as most people envision a young, innocent youth struggling in vain against the inevitable sentence of death. However, with the recent advances in diagnostic tools, treatment and supportive care, pediatric cancer is no longer synonymous with death. Today, more than one-half of the children

diagnosed with cancer are surviving. Survival indicates that 5 years from the diagnosis of cancer the child is off treatment with no evidence of disease. "Cure" in childhood cancer has been defined as the supposition that the child will eventually die of old age from unrelated causes (van Eys, 1977).

The stresses experienced by a family whose child has been diagnosed with cancer, whether potentially curable or not, are obviously multiple and complex. Theoretically, it is known that the stress of illness in a family member is likely to have ramifications throughout the family system (Beavers, 1977). Social system theorists emphasize that relationships are noted to be circular, or mutually interdependent, such that if any part is touched, the whole system is affected. What affects one child in the family affects all other members. The stresses of a child's illness frequently cause shifts in the manner in which all family members interrelate. These shifts have great impact on siblings' behavior and place all family members at risk for emotional problems (Futterman & Hoffman, 1973).

As noted earlier, more than half of all children now diagnosed with cancer are surviving and are potentially "cured." "Cure," however, is usually achieved only at the expense of intensive and long-term treatment regimes, and the "duration of cure" or the long-term survival rate remains unknown.

Adaptation to childhood cancer differs therefore from that for almost any other childhood illness whether chronic or acute. Advances in the treatment of childhood cancer have created a new category along the health-illness continuum. This category may

be termed "acutely-chronic-illness" in which a potentially fatal illness is treated over a protracted period of time for potential long-term cures. Patients in this category may initially be seriously and acutely ill and subsequently experience chronic disruption or varying degrees of impairment due to intensive therapy for as long as three years, after which they are pronounced "potentially cured." They must then, however, live their lives with the "sword of Damocles" above their heads hanging upon the "if-thread". . .the child is healthy and is cured if the disease does not return.

What effect does this experience have on siblings of children diagnosed with cancer? Do anxieties, disruptions and adaptations differ dependent upon the treatment status of the diagnosed child? Is anxiety measurable and/or predictable in these children?

The literature is replete with research about the psychosocial impact of pediatric cancer. However, most of this work has focused solely on the terminally ill child or on parents of the terminally ill child. Certainly these investigations represent an important step in identifying anxieties, stresses and adaptation processes of families with a child dying of cancer, but little is mentioned about the family living with cancer or about anxieties and adaptation processes specific to siblings of the child with cancer.

In a survey regarding the significance of different life events of children, Coddington (1971) found that for both

elementary and junior high school age children, serious illness of a brother or sister required almost as much adaptation in terms of life change units (adapted from Holmes, 1967) as serious illness requiring hospitalization of the child himself.

In research of family reactions to chronic illness or to the death of a child, siblings have been found to be the most severely affected second only to the mother (Findlay, Smith, Graves & Linton, 1969; Gyulay, 1976). "I hurt too, you know, only I hurt in my heart!" This true statement, uttered by a distraught six-year-old sibling of a child diagnosed with leukemia, reflects the anguish and anxiety siblings experience in a family where a child has been diagnosed with cancer.

The lack of research in this area reflects both the former failures for long-term survival in pediatric patients with cancer, and the previous focus of "patient-centered" rather than "family-centered" health care delivery. Previous studies that have been completed have focused primarily on adaptation to the stresses of inevitable death of the child diagnosed with cancer. The situation has now changed from anticipation of death to the anticipation of the possibility of a normal life span. Although life for these families is encompassed in uncertainty, this change in realistic hope for potential cure creates a whole new spectrum of anxieties and requirements for adaptation.

Another new factor affecting the stress and anxieties experienced is the enlightened cultural understanding that children have the right and the need to know what is happening to them.

Previous research regarding anxieties of children with cancer was conducted at a time when societal beliefs maintained that children should not be informed about the nature or seriousness of their illness. As Waechter (1968; 1971), Spinetta (1973; 1975) and others have documented, this cloak of silence only heightened the anxiety children experienced.

Problem Statement

Although much research attention has been given to the needs and the psychosocial reactions of children with cancer, and their parents, limited information is available regarding the needs of siblings and the anxieties they may experience. Previous studies with terminally ill children diagnosed with cancer have found that those children experience much greater anxiety than chronically ill, acutely ill, or healthy children (Waechter, 1968, 1971; Morrissey, 1965; Spinetta, 1973, 1975). This investigation was designed to assess the anxieties that siblings of children with cancer experience and to determine if the amount and/or type of anxiety expressed varied relative to the treatment status of the child with cancer. The physical condition of the child with cancer was categorized as (1) receiving treatment for cancer, (2) having completed treatment for cancer, or (3) having died from cancer.

Review of the Literature

Authors reporting the effects of chronic illness on family adaptation have noted that the stress of chronic illness

frequently creates unique emotional and material strains on family relationships, family welfare and the family's adaptive capacity (Abram, 1972; Mattson, 1972; Prugh, Staub, Sands, Kirschbaum & Lenihan, 1953; Travis, 1976; Waechter, 1971). Other studies focused on family adaptation to chronic illness have revealed that the concentration of both emotional and financial resources in behalf of the ill child frequently have repercussions in heightened rivalry, jealousy and feelings of relative deprivation in non-ill siblings (Maddison & Raphael, 1971; Minde, 1978; Steinhauer, Mushin & Rae-Grant, 1974).

In general research of family adjustments to chronic illness several factors which influence the anxieties and adjustment of non-ill siblings have been identified. These include the following:

1) Frequency and openness of discussion between parents and siblings (Findlay et al., 1969; Turk, 1964; Waechter, 1971).

2) Previous family relationships (Gourevitch, 1973; Lawson, 1977; Travis, 1976).

3) Family constellation (Adler, 1964; Meyerowitz & Kaplan, 1967).

4) Extent to which non-ill sibling is involved in satisfying activities and peer relationships outside the home (Erickson, 1963; Meyerowitz et al., 1967; Sullivan, 1953).

5) Non-ill sibling's previous experience with loss of a parent or sibling through death, separation or divorce (Bowlby, 1960; Feinberg, 1970; Meyerowitz et al., 1967; Waechter, 1971).

6) Sex differences (Lawrence & Ryan, 1979).

Although the previous investigators of families adapting to chronic illness have revealed various sibling responses and a variety of factors which may affect sibling anxieties and adaptation, there are very few controlled, objective studies having focused specifically on siblings alone. Research quantifying the frequency of disturbance among siblings of children with chronic illness, or research using comparative sibling groups of children with different illnesses is rare.

Tew and Lawrence (1973), who were the first to utilize a comparative control group in sibling research, found that siblings of patients with spina bifida were more than four times as likely to show signs of maladjustment in school than were siblings of healthy control subjects. No differences in adjustment as a function of birth order were found, but a non-linear relationship between the severity of illness and sibling adjustment was identified. Siblings of children with only slight handicaps were the most disturbed, followed by those with severe handicaps and finally, moderate handicaps.

In another comparative sibling study Gath (1972) compared siblings of children with surgically repaired cleft palates, siblings of children with Down's syndrome and siblings of healthy children in a control group. No elevated incidence rates in adjustment problems were found. The discrepancies between these two investigations suggest that factors specific to each different illness may influence the effect of illness on

sibling's adaptation.

Illnesses differ on a complex array of characteristics including chronicity, severity, certainty of illness course, costs, and amount of family disruption caused by home treatment and hospital contacts. Any of these characteristics, alone or in combination, may influence sibling anxieties and sibling adaptation. The effects then of illness may be specific to each disease process.

Lavigne and Ryan (1979) conducted one of the first investigations of siblings of children with cancer and attempted to examine the possible effects of disease differences in siblings of children in three different illness groups. Siblings of cardiac, hematology-oncology and plastic surgery patients were compared with a control group of healthy siblings. A standardized measure, the Louisville Behavior Checklist, was utilized to measure children's emotional and behavioral problems. This true/false measurement assessed parents' perceptions of children's problems, rather than testing the children themselves. A variety of significant differences were identified.

In terms of overall disturbance or general psychopathology, siblings aged 7-13 years showed no significant differences among the four groups. Combining all groups and all ages, however, revealed significant sex differences. Male siblings tended to show more behavior disturbances than females in the healthy control group, and male siblings of hematology patients displayed more behavior problems then female siblings of

hematology patients. This sex difference is not unexpected, however, since investigations of children typically reveal more signs of behavior problems among boys then among girls.

On the social withdrawal scale, siblings in the combined illness groups showed significantly more withdrawal than healthy controls. Combining both groups of siblings of children with non-visible illnesses, it was found that siblings of patients with visible handicaps were significantly more withdrawn than those with nonvisible illnesses. However, the hypothesis that siblings of children having potentially shorter life expectancy would have greater neurotic tendencies or more withdrawal was not supported.

Analysis of irritability revealed significant illness group differences. The siblings of combined patient groups showed greater irritability than siblings of the healthy control group. Also, siblings of the visible illness group were more irritable than siblings in the two nonvisible illness groups, cardiology and hematology-oncology.

Analysis of sibling age and its effect on sibling adjustment revealed no significant differences for age relationship to the patient. There was, however, a nearly significant main effect for age on the social withdrawal scale, with younger siblings being more withdrawn than older siblings.

Sex and age interaction on sibling adjustment did reveal significant differences. Older girls tended to show fewer indices of adjustment problems than older boys, whereas younger girls

showed higher levels of adjustment problems than younger boys. Although Lavigne and Ryan's original hypothesis stated that younger siblings would be more affected by illness than older siblings these findings suggest that the relationship is somewhat more complex and differs for the two sexes.

Attempting to correlate illness-related variables such as chronicity and the severity of illness, numbers of hospitalizations and numbers of clinic visits with the degree of sibling adjustment problems unexpectedly revealed no significant correlation on scales of total aggression, social withdrawal, inhibition, fear, irritability or total psychopathology. This is contrary to the general belief that the more severe the illness, the greater the adjustment problems.

Most of the literature dealing with the adaptation of families to the problems of chronic illness in children implies that chronic illness as a stressor invariably results in damaging psychological consequences for the child and his family members. Long-term studies, however, regarding family adaptations to chronic and/or fatal illnesses, remain inadequate.

Gayton, Friedman, Tavorinina and Tucker (1977) attempted to assess the problems of long-term adaptation with families of children with cystic fibrosis. Patients, siblings and parents in various stages of adaptation were tested with a variety of formal psychological evaluations as well as semi-structured interviews. Three tests were used with 23 patients and 26 siblings; these tests included the (1) Piers-Harris Self-Concept

Scale, (2) Missouri Children's Picture Series, and (3) Holtzman Inkblot Test. The results provided only partial support to current concepts regarding the totally disruptive effect of chronic illness upon patients and their families.

The negative psychosocial consequences for personality function and family interaction were not as severe as many previous authors have implied. This is not to say that these families experienced no difficulties at all, but that the long-term problems were manageable and less devastating than anticipated. Both patients and siblings scored well within normal limits on psychological test performance scales (siblings in fact scored higher than normal children in terms of the averaged total self-concept scores).

Although there is agreement that chronic illness in children serves as a psychological stressor to all family members, "this does not preclude the utilization of coping devices which allow the chronically ill child and his family to develop healthy adaptations" (Gayton et al., 1977, p 893).

Many authors tend to emphasize that the stigma of cancer and its "synonomous association with death" increases anxieties in family members such that maladaptive behavioral responses are the only outcome to be expected. However, actual studies of long-term effects on family adaptation in families with children diagnosed with cancer are limited. Research focused specifically on sibling anxieties and adaptation processes in these families are practically nonexistent. Some of this

deficiency is understandable considering that advances in treatments and potential cures in childhood cancer have come about only within the last decade, thus most research that has been done has focused on families of the child dying with cancer.

Siblings of a Child who has Died

There have been many attempts to discern anxieties, reactions and adaptation of children following the death of a sibling; most have addressed what adults perceived, and most have sought to demonstrate retrospectively that the experience of life-threatening illness and death results in maladaptive behavioral responses in surviving children.

An early major sibling study of 58 children between the ages of 2½ and 14 years who developed psychiatric problems following the death of a child in the family supported this viewpoint (Cain, Fast & Erickson, 1964). These children were found to have a variety of disturbed reactions.

Severe guilt reactions were most prominent. Many children felt responsible for the sibling's death, sporadically insisting it was their fault. They also felt that they should have died too, or have died instead of the sibling. Many of these children believed that they deserved only the worst, insisting that they should enjoy nothing.

Guilt was expressed in a variety of reactions including depressive withdrawal, punishment-seeking, accident-prone behavior, constant provocative testing, exhibitionistic use of guilt and

grief, many forms of acting out and massive projection of superego accusations. These children frequently experienced consequent deterioration in functioning, especially in school, which provided them with further grounds for insisting that they were worthless and rotten.

Cain et al. (1964) found many children to have distorted concepts of illness and death. The interpretation of almost one-third of the children was that growing up or growing older meant dying, and they therefore retreated in partial or total defensive regressions toward passive-dependent infantalism. These children also feared disease or any health problems with frighteningly concrete disease notions (cough, high fever or bruises would lead to death). Death became constantly imminent, and these children confused parental urgings and cautionary tales about food, sleep, and clothing and elaborated them into causes of illness and death.

Children's notions about parental strength as protectors, parental invulnerability and all-powerfulness were destroyed. These youngsters felt extremely vulnerable and virtually all of them developed a very intense fear of death. They were convinced that they, too, would die either at precisely the same age or from the same cause or under the same circumstances as the dead sibling.

Parents in these particular cases typically had developed fearful overprotectiveness of the remaining siblings in response to the death. This sometimes phobic vigilance restricted siblings

from many basic growth experiences and produced children who were generally immature, fearful, passive-dependent and feeling inadequate, and vulnerable.

It was also found that these parents frequently misidentified the remaining children with the dead child, making comparisons and expectations based on the idealized image of the dead child. The authors noted: "These remaining children found the strange task of being, yet not being, the dead child," (Cain et al., 1964, p. 748). They felt hopeless and resented their parents' expectations; they were aware of their parents' basic wish that they, not the brother or sister, had died.

Cain et al. found that this consistently unfavorable comparison between the surviving child and the dead sibling occurred in almost one-half of the cases. Although these comparisons were found to extend over all areas of behavior, they were particularly focused upon school performance.

One last aspect of parental behavior found to affect siblings in at least one-fourth of the families was the parents' profound grief reactions and prolonged mourning. Mothers were often completely incapable of providing any love for, or even attention to the remaining siblings. When death followed a prolonged illness requiring hospitalization, siblings lost not only maternal love and concern as she became overwhelmed and preoccupied with the ill child, but non-ill siblings felt the loss of her physical presence as well. Many siblings saw illness as the only means to reach their mother.

The researchers concluded the following factors as determinants of childrens' response to the death of siblings:

1) The nature of the death

2) the age and characteristics of the child who died

3) the child's degree of actual involvement in the death

4) the child's preexisting relationship to the sibling who died

5) the immediate impact of death upon the parents

6) the parents' handling of the initial reactions of the surviving child

7) the death's impact on the family structure

8) the parents' enduring reactions to the death

9) major concurrent stresses upon the remaining children and parents and

10) the developmental level of the surviving child at the time of death, including the psychosocial and ego development with particular emphasis upon the cognitive capacity to understand death.

Others have also outlined these factors as influential in sibling anxieties and adaptation to the death of a child in the family (Berman, 1978; Maddison & Raphael, 1972; Lascari, 1978; Schoenberg, 1973; Wiener, 1970).

Siblings of Children Dying of Cancer

Cobb (1956), one of the earliest to investigate family adaptations specifically to childhood cancer and to death of the child with cancer, noted that siblings became preoccupied

with minor illnesses and displayed both behavioral and academic problems in school. Retrospective research by Binger, Albin, Feurstein, Kushner, Zoger, and Nikkelson (1969) revealed that in 20 families of children who had died of leukemia, almost one-half of the non-ill siblings within these families showed later psychological difficulties after the sibling's death, even when they had appeared earlier to be well adjusted. Psychological difficulties or reactions included headaches, severe enuresis, persistent abdominal pains, poor school performance, school phobia, depression and severe separation anxieties.

The investigators also noted that non-ill siblings expressed feelings of guilt and responsibility for the sibling's illness and death, fears that they would be next, anger at the parents who "allowed" the sibling to become ill and resentment of parents preoccupation with the sick child. Some children misintrepreted their parent's preoccupation with the ill child as a rejection of themselves and these children developed a preoccupation with inner fantasies around death.

Stehbens and Lascari (1974), in a similar retrospective investigation of 20 families, gathered data from parents within 6 months to 3 years following the death of a child from leukemia. Almost 20 percent of these siblings were described as having problems related to sleep, enuresis, transient abdominal pain and school problems.

In another study, Albin, Binger, Stein, Kushner, Zoger and

Mikkelsen (1971), reported the reactions of jealousy in siblings who resented the extra attention received by the dying child. These siblings also expressed feelings of anger with the disrupted family life caused by the illness. Feinberg (1970) noted that siblings of a child dying of leukemia expressed a desire to get sick and had feelings of anger, guilt and depression.

One last investigation focused upon family responses, including siblings' responses, three months post-mortem to having lost a child with leukemia (Kaplan, Grobstein & Smith, 1976). This was an attempt to identify relationships between early family coping reactions after the diagnosis and stress outcome. Is initial coping response to crisis an indicator of long term adaptability?

The investigators found that three months after the death of the child with leukemia, only 30 percent of the families felt that they were coping well with minimal problems. Looking at sibling response in particular, parental reports indicated that 48 percent of all siblings experiences at least one or more post-mortem problems which had not been evident prior to the diagnosis of the brother or sister with leukemia. These problems were not specified in the report except for a tally of children with school performance problems which was reported at 43 percent.

The authors did find significant positive correlation between those families with adaptive coping skills evidenced

early after diagnosis and reports of minimal problems three months post-mortem. Although the period of only three months post-mortem limits the applicability to truly long term adaptability, this correlation may indicate potentially long range adaptive skills.

Siblings of Children Living with Cancer

One of the first examinations of the impact on siblings of children living with cancer was completed by Gogan, Koocher, Fisher and O'Malley (1977). Although only a total of 13 siblings from eight families were interviewed, the results are pertinent for those concerned with "family oriented" care. This retrospective investigation was an attempt to assess through personal interviews the siblings' perceptions of their experiences of the diagnosis of cancer in a brother or sister five or more years prior to the interview. All children diagnosed with cancer had been treated, were still alive and free of disease and were thus survivors of five years or more. A variety of forms of childhood cancers were included.

There is some degree of distortion and lost affect in retrospective reports, especially with young people whose cognitive abilities at the time of the recalled events were somewhat limited. The median age of the siblings at the time of the patient's diagnosis was four years; eight were under 5, two between 6 and 10, and the other three were between 11 and 17 years of age. Despite the potential distortion, the advantage

of the retrospective format was gaining some perspective on the actual long-term effects of earlier crisis and adaptation.

In discussing the period of diagnosis and treatment, many siblings did not remember it as being particularly traumatic to them. Many, however, were young at the time. The siblings who were older at the time of diagnosis, especially the three teenagers, did remember feeling somewhat alone and detached. They attributed this exclusion to their scholastic and social activities. The lack of involvement or participation in discussions may have also, however, reflected an unwillingness of parents to discuss the illness or its possible ramifications.

Other researchers, working with cystic fibrosis families, found that parents may simply suppress any communication about feelings, fears, or even future plans (Meyerowitz & Kaplan, 1967; Turk, 1964). This attempt to "suppress" information is usually in the guise of "protecting the children", although it may also be an attempt to keep themselves safe as well as to avoid feelings and fears they do not want to face.

Gogan et al. (1977) suggested that non-ill siblings may also suppress communication and/or feelings. Reacting to parental cues, non-ill siblings may "bury" feelings of exclusion as well as fears and concerns about the illness. Non-ill siblings try to protect parents as parents try to protect the non-ill siblings. A bond of silent conspiracy develops among family members in an effort to maintain "status quo." The facade, however, remains very delicate and may crumble

easily as each family member struggles to keep fears, myths, and misconceptions in place.

Problems of sibling rivalry and guilt normally seen between siblings were noted by non-ill siblings to be augmented with the stress of the illness. Non-ill siblings not only remembered "special treatment" for the patient during the course of the illness and treatment, but many reported continued favoritism despite currently good physical health. Feelings of guilt, another frequently reported problem experienced by siblings, did not appear to have had any long-term effects in this small sample except for one. Young siblings who cannot decipher the discrepancies between magical thinking and logical thought have often felt responsible for the illness and even the death of a sibling. One seventeen year old girl still experienced feelings of guilt and responsibility thirteen years after the diagnosis and treatment of her brother's Wilm's tumor. She, at four years of age, "let him fall off the couch" and when he later had a nephrectomy she was told that he had to lose his kidney because the fall had injured it! (Gogan et al., 1977).

Iles (1979) in a pilot study of five siblings of children with cancer attempted to identify what healthy siblings perceive their experience to be during the different phases of the patient's illness. Five siblings between the ages of 9-11 years were selected to represent each of the following stages of the childhood cancer experience: onset of treatment; first remission; first relapse; subsequent remission; and terminal status.

Semi-structured interviews were conducted with each child using open-ended questions to elicit perceptions regarding the ill child, the sibling's current experiences and his perceptions of family life. Each child was also requested to draw a picture of the family.

Utilizing the grounded theory perspective, perceptions were grouped into major categories of phenomena after analysis of the data (Glasser & Strauss, 1967). The pervading theme related by all siblings was one of change. Changes in interpersonal relationships and in the external environment were the two dominant areas of experience repeatedly identified by all siblings in which change was consistently perceived.

Four main categories of potential loss resulting from the changes were also identified consistently by siblings. These categories included:

1) Disruption of interpersonal relationships (especially parents, ill siblings, and peers)

2) physical distortion of the ill sibling

3) disturbances in the routine of family life and

4) alterations in the environment (such as empty house and parent substitutes).

Although the data gathered continue to identify areas of great stress and anxiety in siblings of children with cancer, the experience is not inherently negative or destructive for siblings. Even in this small sample, evidence of personal growth was obvious. Gains in self-concept, in cognitive under-

standing, respect for the ill sibling, and empathy for parents' needs were noted to permeate the data.

The first major research to compare siblings of children diagnosed with cancer and the patients themselves was done by Cairns, Clark, Smith and Lansky (1979). These investigators tested school-age patients and their healthy school-age siblings (6-16 years) from 71 families who had children currently undergoing treatment for various childhood cancers. Assessment instruments included the Piers-Harris Children's Self-Concept Scale, the Bene-Anthony Family Relations Test and the Thematic Apperception Test. These tools tested the children's perceptions of themselves, evaluated perceived roles in the family system and elicited other concerns central to the children.

Cairns et al. (1979) found both patients and siblings to be essentially normal. Both groups, however, had significantly high anxiety scores and negative body images. Anxieties experienced by both patients and siblings entailed fears regarding personal vulnerability to illness and injury. Although no one has proposed that siblings remain immune from the psychosocial traumas of cancer diagnosis and treatment in a brother or sister, this was the first documentation of the impact upon both groups.

Differences between siblings and patients, however, were also found. Siblings showed greater distress than patients in their perception of parental overprotectiveness and overindulgence of the patient. Siblings also perceived greater social isolation and greater fear of confronting family members with negative

feelings. The interactive effect of age was also identified, with older siblings showing the greatest concern about failure. Older siblings in fact (those over 10 years) had four times as many failure responses as the patients and younger siblings.

However, the conclusions reached by these investigators do not suggest that the diagnosis and treatment of cancer in a sibling results in abnormal behavior in non-ill siblings. Although the siblings remain under a great deal of stress and anxiety, Cairns et al. emphasized that the non-ill siblings were essentially normal.

Death Anxiety

The dying child's awareness of impending death as measured by his expression of anxiety regarding death has been the subject of numerous studies. The majority of these investigations were done at a time when society believed it was in the best interest of the child to keep the diagnosis and prognosis secret from the child. They were also based primarily on interviews with parents and/or observations of the fatally ill children. Very few utilized direct assessment of the children's anxiety and/or attitude towards their own diagnosis and impending death. If children were not allowed to know the nature of their illness, observational studies and interviews with parents were the only method identified to assess children's anxieties.

Researchers themselves were not ready to approach children directly. The design of the early studies reflected the cultural insecurities in dealing directly with dying children. Adult

anxieties produced reluctance to face the reality of the child's death.

Of the early research done to assess anxieties and the psychological reactions of the dying child, that of Richmond and Waisman (1955) stands out as an important effort. From an observational study of 48 children with cancer (no ages were identified), Richmond and Waisman reported that fatally ill children rarely manifested an overt concern about death. However, these children were noted to react to their illness with an air of passive resignation and acceptance.

> "Even among adolescents, who intellectually know much about cancer, the question concerning diagnosis and possibility of death usually was not raised as it often is by the adult patient. Our suspicion is that this does not reflect an unawareness, but rather represents an attempt at repression psychologically of the anxiety concerning death." (Richmond & Waisman 1955, p.43)

Natterson and Knudson (1960), in a similar observational investigation of children diagnosed with cancer identified a maturational pattern of death fears. From their study of 33 children, age 0-13 years, they concluded that the focal point of the child's anxiety was directly associated with their ages. This pattern reflected the findings of Maria Nagy (1948) whose research indicated that children under 9 years of age could not cognitively grasp or conceptualize the reality of death as a permanent biologic process.

Natterson and Knudson identified three phases of children's reactions and concluded that only the oldest children actually reveal anxiety or apprehension related to their impending death.

The children under 6 years of age were most concerned with separation; the child from 6 to approximately 10 years was most fearful of physical injury and mutilation. The authors noted that this evolution of fears is related to the maturation of consciousness.

> "The child is first aware of his mother, then of his own body, and finally of himself in time (i.e., of life itself)" (Natterson & Knudson, 1960, p. 460).

They indicated that their observations suggested that separation, mutilation and death fears are separate and distinctive. To support this they noted that between 6 and 10 years of age, manifestations of death fear were vague and evanescent. Expressed anxiety was instead generally related to intrusive or painful procedures. They did admit, however, as did Richmond and Waisman, that anxiety about death may be present in a subtle form in younger children.

Morrissey (1963) attempted to ascertain death anxiety in children hospitalized because of leukemia. Based on a sample of 50 hospitalized children, this investigation was again observational by design. Twenty-nine children were under 6 at the time of their death, a few were between the ages of 6 and 9 and 16 children were 10 or older.

Three primary sources provided data for assessment. These sources included: 1) the medical charts, authored primarily by physicians and nurses; 2) data related to the child's family background and parents, the primary informant being the hospital social worker who had frequent contact with the parents, and 3) weekly interviews conducted and tape-recorded by the author with a variety of staff personnel, nurses, physicans and occupational therapists.

Although Morrissey (1963) allowed that a younger child may

be capable of experiencing death anxiety, he concluded that in general, anxiety related to death is not experienced until the child is at least 9 or 10 years of age. Morrissey also observed that children handle death in different ways: 1) younger children probably express it symbolically and physiologically, 2) older girls are prone to become depressed, and 3) older boys tend to act out.

As in previous studies, however, Morrissey's reliance on observational data and his dependence on overt expressions concerning death as the basic indicator of the child's anxiety provided inconclusive findings. Research based on data gained directly from the child was needed.

Waechter (1968, 1971) in a pioneering investigation dealt directly with the child to measure objectively the child's anxiety response to illness. This research was based on the assumption that despite the attempt to protect the fatally ill child from knowledge of his prognosis, the altered climate, and the evasiveness or false cheerfulness of meaningful adults conveyed to the ill child the anxiety felt by adults.

Indirect and fantasy expression of the child's concern for present and future body integrity and functioning were elicited through the use of a set of eight pictures. Stories were requested for each of the pictures from each of the 64 children in the study. Waechter (1968) used four matched groups, 16 each, of children within the 6-10 year age range. These groups included: 1) hospitalized fatally ill children; 2) hospitalized children with non-fatal, chronic illnesses, 3) hospitalized children with a brief

illness; and 4) normal, nonhospitalized children.

Waechter (1968) also administered the General Anxiety Scale for Children (Sarason, Lighthall, Davidson, Waite & Ruebush, 1960) which measures concerns in many areas of a child's life. Maternal interviews were also conducted to assess the possible influence of variables which may have influenced the quantity and the quality of the ill child's concerns related to dying or to death. These variables included the quality of maternal warmth toward the child, the religious devoutness within the family, the child's previous experience with death and the opportunity the child had had to discuss his concerns or the nature of his illness with his parents, professional personnel, or other meaningful adults.

The findings showed that the fatally ill children scored twice as high as the other hospitalized children on the total anxiety score of the General Anxiety Scale. This result supported the prediction that although only 2 of 16 children were told their prognosis, the generalized anxiety level was very high.

Themes of loneliness, separation and death were also reported much more frequently in the fantasy stories told by those children threatened with death. The other groups expressed a greater degree of concern with threat to and intrusion into their bodies and interference with normal body functioning.

Another important finding was the dichotomy between the parents' belief about the fatally ill child's awareness of his prognosis and the degree of awareness the child revealed through his imaginative stories. Although less than 13 percent of the

fatally ill children knew their prognosis, 63 percent of the stories told by these children related to death themes. This again supports the assumption that the child does receive information regarding the seriousness of his illness through the nonverbal communication of those around him.

In contrast to the cultural belief of the time, Waechter (1968) found a highly significant correlation between the degree to which the child had been given an opportunity to discuss his fears and prognosis and the child's total anxiety score on the projective test. The children who had had the opportunity to discuss their illness expressed much less anxiety or feelings of loneliness, isolation or alienation than those children who had not been allowed to discuss their fears and prognosis.

Although trends were identified regarding the influence of religious instruction and previous experience with death, no significant correlation between these variables and measurable anxiety were identified. Waechter did note, however, that the child's fantasy about his own future may be influenced by his previous experience with death and how he was supported during the former experience. Waechter's findings (1968) strongly supported the assumption that children aged 6-10 years with a fatal prognosis are not only aware they are dying, but that they can also use words relating to death to express that awareness.

These findings were significant especially at a time when the general approach perpetuated by parents and health professionals supported the belief that children should be spared the knowledge

of their diagnosis and/or prognosis. This research indicated that despite the attempts to shield fatally ill children from their diagnosis and/or prognosis, the nonverbal communication of anxious adults conveyed to the child the seriousness of his illness. Findings also revealed the significant amount of anxiety experienced by sick children.

Once this door of awareness was opened and the reality exposed, other investigations were conducted in attempts to clarify the issue of overt expression of anxieties in sick children, and particularly death anxieties in fatally ill children. Spinetta, Rigler and Karen (1970) designed an investigation to test Waechter's conclusions about the higher level of anxiety in fatally ill children in the 6-10 year age group. This study, however, was designed to assess possible death anxiety without relying on overt expression about death for the measure of this anxiety.

It was predicted that children's anxiety would be directly related to the seriousness and fatality of the illness experienced. Also, because of the awareness of the seriousness of their illness, it was predicted that fatally ill children, without mentioning death overtly, would show a much greater preoccupation with threat to body integrity and functioning and a greater overall anxiety relative both to the hospital and to nonhospital related situations than would a control group of chronically ill hospitalized children.

Fifty children were tested, 25 hospitalized with the diagnosis of leukemia and the remaining 25 with chronic nonfatal

illnesses. The chronically ill group was matched to the fatally ill in age, sex, race and grade in school. The subjects were also matched as closely as possible in terms of frequency and intensity of hospital experiences, amount of medical intervention and seriousness of condition.

Each child was given a brief anxiety questionnaire adapted from the State-Trait Anxiety Inventory for Children (Spielberger, Edwards & Montouri, 1972). The purpose of this test was to sort out hospital anxiety from home anxiety. The children were also asked to tell stories about each of four pictures of hospital scenes and about each of four figurines (nurse, doctor, mother, and father) placed in a three-dimensional replica of a hospital room.

These researchers found that the children diagnosed with leukemia related significantly more stories showing preoccupation with threat to and intrusion into their bodies and interference with their body functioning than did the chronically ill children. This finding was true both in the stories relating to the pictures and the stories told about the placed figurines. The fatally ill children also expressed both more hospital-related and nonhospital-related anxiety than the chronically ill children.

This study supported again the knowledge that despite efforts to keep the child with a fatal illness from becoming aware of his prognosis, the message is conveyed to the child that his illness is very serious and very threatening. It also indicates, as did Waechter's study (1968) the significant amount of anxiety these

children diagnosed with a malignant disease experience. Two questions arise. First, since all children diagnosed with cancer were hospitalized when tested, how much of this awareness and anxiety is hospital related? And secondly, has the anxiety level of these children, diagnosed with a malignant disease, decreased with the advances of treatment and the opportunity for realistic hope regarding long term prognosis?

The first question was addressed by Spinetta and Maloney (1975) who repeated the original Spinetta study (1973) using groups of outpatient children aged 6 to 10 years. Thirty-two children were tested, 16 being treated for leukemia and 16 treated for chronic illnesses that were not fatal. The chronically ill children were again matched as closely as possible to the fatally ill children in age, duration of illness and number of hospitalizations. Hypotheses were similar to those in the first study. It was predicted that the fatally ill children, although in remission and being treated as outpatients, would again show greater overall anxiety relative to both the hospital and to home; that the fatally ill children would place significant hospital figurines at greater interpersonal distance than would the controls; and that the fatally ill children would tell stories relating greater preoccupation with their illness than the matched control group.

The results were similar to Spinetta's first investigation (1973). The child with leukemia, in remission and being tested on an outpatient basis, continued to express greater anxiety despite his out-of-hospital life. These children also exhibited a

greater preoccupation with threat to their body integrity and functioning and a lack of adaptability to the necessity of clinic visits. Clinic visits became more anxiety-provoking for children with leukemia as the duration of the illness and frequency of the clinic visits increased. The older leukemic children also expressed greater anxiety than younger children.

The lack of contrast in interpersonal distance between the leukemic and the chronically ill children was the only major difference noted between this research of outpatient children and the earlier study of inpatients. Although the leukemic child in remission expressed greater anxiety related to his vulnerability to bodily harm, his anxiety did not take the form of separation from the significant figures in his hospital life.

Statement of Purpose

The purpose of this investigation was to assess anxieties of siblings of children with cancer and to determine if the amount and/or the type of anxiety expressed varied relative to the treatment status of the brother or sister with cancer (receiving treatment, completed treatment or dead).

Research Questions

Based on previous work regarding anxiety and adaptation, the following research questions were proposed:

1) Do children (identified as subjects) aged 6 to 10 years of age whose brother or sister has been diagnosed with cancer, express significantly greater anxiety as measured by the General

Anxiety Scale for Children (GASC) than subjects of a comparison group who have not experienced a chronic or potentially life-threatening illness within their families?

2) Does anxiety as measured by the GASC vary significantly with changes in the treatment status of the child with cancer?

3) Do subjects whose brother or sister has been diagnosed with cancer express significantly greater anxiety on the Projective Picture Test (as measured by the Total PPT Anxiety Score) than subjects of the comparison group?

4) Does anxiety as measured by the Total PPT Anxiety Score vary significantly with changes in the treatment status of the child with cancer?

5) Does the subject's Total Anxiety Score (as measured by the sum of the GASC and Total PPT Anxiety Score) change significantly relative to the treatment status of the child with cancer?

6) Do subjects who have had the opportunity to discuss their concerns and the nature of the patient's illness express less generalized anxiety (as measured by the GASC and the Total PPT Anxiety Scores) than subjects who have not had this opportunity?

7) Do mothers perceive a change in the subject's behavior after the diagnosis and/or death of the patient as measured by the Behavior Change Scale?

8) Do subjects who have experienced a death in the immediate family, or who have had other significant death experiences,

express more anxiety (as measured by the GASC, the Total PPT Anxiety Score, and the Total Anxiety Score and death themes) than those who have not had this experience?

CHAPTER II

METHODOLOGY

Design of the Study

This project was a low-risk study designed to assess the anxieties of school-aged siblings of children with cancer. It was based on similar research by Waechter (1968), which assessed anxiety in school-age patients of varying levels of wellness (fatally ill, chronically ill, acutely ill and healthy children).

Based on theoretical understanding of family system adaptation and on personal experience with siblings of children with cancer, it was assumed that these children, siblings, experience anxiety as they adapt to the experience of cancer diagnosed in a brother or sister.

Subjects were shown a set of eight pictures and asked to tell a story about each picture to elicit indirect and fantasy expression of the child's concerns related to present and future body integrity. A General Anxiety Scale for Children (GASC) that measures concerns in many areas of living was also administered individually to each child. Parents of the children were requested to respond to a parent interview

designed specifically for the study.

Subjects

The subjects for this study were 32 healthy children between 6 and 10 years of age inclusive, who had a sibling diagnosed with cancer. These children henceforth will be referred to as subjects, and children diagnosed with cancer will henceforth be referred to as patients.

Subjects were divided into three groups according to the treatment status of the patient as follows:

Group A) Siblings of children in remission currently receiving treatment for cancer. (n=15; 9 families)

Group B) Siblings of children in remission, who have completed treatment, having received treatment for cancer within the last three years. (n=9; 8 families)

Group D) Siblings of children who died of cancer within the last three years. (n=8; 8 families)

Group ABD) For purposes of analysis, these three groups of siblings were combined and referred to as the combined sibling group.

All subjects were at least four years of age at the time the patient was treated for cancer or at least four years of age when the patient died of cancer. Age and sex distribution of the subjects are shown in Table 1.

Neither the age of the patient nor the specific type of cancer diagnosed was controlled. Patients were categorized by

Table 1

Sex and Age Distribution of Sample

Group	n	Males	Females	6 yr.	7 yr.	8 yr.	9 yr.	10yr.
Combined Sibling Group ABD	32	15	17	6	4	8	7	7
Patient receiving treatment A	15	6	9	3	3	4	4	1
Patient completed treatment B	9	6	3	2	-	2	2	3
Comparison Group C	28	13	15	7	7	3	5	6
Patient died D	8	3	5	1	1	2	1	3

diagnosis as follows: Leukemia, 17 patients; solid tumors, 8 patients. Siblings were selected from a total of 25 different patient families.

A group of 28 healthy children between 6 and 10 years of age inclusive, who had no familial history of chronic or terminal illness experiences within the nuclear family and whose brothers or sisters were currently healthy were also tested to represent a control group for comparative purposes. This group was referred to as Group C, and was identified as the comparison group. Subjects in this group were selected from a total of 15 different families residing in the Greater Salt Lake Valley Region. An attempt was made to match sex, age, race and socioeconomic class, but due to the limitations imposed by the available sample, complete matching was not possible. Age and sex distribution of Group C, the comparison group, is presented in Table 1.

Sampling Method

Since the numbers of healthy siblings in the selected age group meeting the criteria were small, it was necessary to accept all children meeting the criteria without using a random sampling process. Subjects for the sibling group were selected from families attending the Oncology Clinic managed by the investigator who requested a parental interview and consent to include the child in the sample. (See the Parent Consent Form, Appendix A). None of the parents refused to participate.

Subjects for the comparison group were randomly selected

from volunteer families within the Salt Lake Valley who had no familial history of chronic or terminal illness experiences within the nuclear family. In as much as possible, sex, age and socio-economic background of the comparison group were matched with the combined sibling group.

Instruments

Instruments were identical to those used by Waechter (1968), with the exception of the Maternal Interview which was adapted by the investigator for this study (See Appendix C).

Projective Picture Test

The Projective Picture Test consisted of a set of eight pictures which were shown individually to each subject by the same investigator. Stories were requested in an attempt to elicit fantasy and indirect expression of the child's anxiety regarding present and future body integrity.

The eight pictures were duplications of those employed by Waechter (1968), and were used with her permission. Four of the pictures were specifically designed by Waechter and four were selected from the Thematic Apperception Test.

Testing was done during a home visit by the investigator to each of the subject's homes. In the event that more than one child in a family was tested, privacy for each subject was maintained as much as possible to reduce the possibility of contamination. The subjects were told that the investigator was interested in the imagination of children and in the stories

children tell. No prompting was given except when necessary to clarify the meaning that specific statements held for the child or to clarify the child's thought. No time limit was imposed.

The following provides a description of the pictures, code number and source:

No.	Description	Source
1	Two boys in adjoining beds	Waechter
2	Small child in hallway outside closed door to ICU	Waechter
3	Boy in front of mural depicting an operation	TAT 8 BM
4	Small child in bed, nurse nearby with back turned	Waechter
5	Figure outlined in open window	TAT 14
6	Child in bed, adults outside door	Waechter
7	Woman entering room, hand on face	TAT 3 GF
8	Small child sitting in doorway of cabin	TAT 13 B

Upon presentation of each picture, the subject was instructed as follows:

"Tell me a story about this picture. Make the story as exciting or as interesting as you can. Include in the story:

1) What is happening in the picture?

2) What has happened before?

3) What are the people thinking, feeling, wanting?

4) What will happen? How does this story end?"

If the subjects persisted in describing the picture, the investigator tactfully reminded the child that the story was requested to test imagination. Pictures were presented to each subject in the same sequence as listed in the table. Stories told in response to the pictures by the subjects were recorded on tape. No time limits were set for the subject and no specific prompting other than the previously stated questions were given. Probing, however, was inserted by the investigator when necessary to delineate the meaning that specific statements held for the child or to clarify the child's thought.

Content analysis of the stories was patterned after that utilized by Waechter (1968) (Appendix G). The taped data were transcribed to facilitate analysis and scoring.

The pictures were chosen to elicit a wide range of imagery related to different types of anxieties with which all children deal when they are ill. These same pictures were selected for this study with the assumption that siblings of ill children also experienced related anxieties in greater proportion than the siblings of healthy children and that the general amount of anxiety expressed varies in relation to the treatment status of the child with cancer. The categories of anxiety expected to be expressed were primarily those identified in previous death anxiety studies (Morrissey, 1965; Natterson & Knudson, 1960; Waechter, 1968; Spinetta, 1973, 1975). These categories include threats to security related to loneliness or separation from meaningful

adults, threats to body integrity (physical illness or body intrusion), and threats related to death itself.

The scoring system was patterned after that designed by Waechter (1968) to determine the primary types of threats or anxiety expressed, the total amount of expressed anxiety or preoccupation with threats, and the outcome of the story.

General Anxiety Scale for Children

The General Anxiety Scale for Children as developed by Sarason and associates (Sarason, Davidson, Nighthall, White & Reubush, 1960) was administered to each subject following the Projective Picture Test. This questionnaire is presented in Appendix B. The questions were originally designed for use as a diagnostic tool to measure general anxiety in school aged children and to predict their difficulty coping with the school environment.

The questions were read to each subject individually by the same investigator. Scoring was determined by summation of the items to which the subject admitted experiencing anxiety. A lie scale was built into the original instrument to allow for determination of amount of distortion in the answers given by each individual subject.

Maternal Interview

A complete interview (Appendix C) was held with the mother of each of the subjects having a brother or sister diagnosed with cancer. In two cases, both parents were present for the interview.

Interviews were tape-recorded and later transcribed for ease of analysis and rating.

The interview schedule was patterned after the Maternal Interview constructed by Waechter (1968), however, several modifications were made to accomodate the sibling perspective and to address the different issues identified. The interview was structured so that the same questions were asked in the same order from all parents interviewed, yet it remained flexible to allow parents to express themselves freely and to avoid the suggestion of "right" answers. The order of presentation and the wording of the questions was controlled to provide for comparability of data.

The purpose of the interview was to elicit information about the variables believed to influence the amount of anxiety expressed by the subject in the Projective Picture Test and the General Anxiety Scale. The variables included: 1) the current health status of the child with cancer; 2) the subject's awareness of the patient's diagnosis, treatment, and prognosis based on the amount of parental verbal interaction with the subject about these issues; 3) the subject's previous experience with serious illness and death; and 4) the subject's overt expression of anxiety as perceived by the parent (behavior changes such as increased somatic complaints or sleeping problems after the diagnosis of the child with cancer). Information related to these variables was elicited through specific questions during the interview.

The parent interview also elicited information not specific to the variables under study but which was important for general assessment of: 1) family constellation; 2) general sibling relationships; 3) the subject's general health; 4) the parent's perceptions of the subject's fears; 5) the parent's understanding of the patient's diagnosis, treatment and prognosis; 6) preparation given to the children for hospitalization; and 7) problems which parents encountered during the patient's hospitalization and at home.

Rating scales for the assessment of the subject's previous experience with serious illness and death and for the subject's awareness of the patient's diagnosis, treatment and prognosis were adapted from rating scales developed by Waechter (1968). A behavior change rating scale for assessment of the subject's overt expression of anxiety as perceived by the parents was developed by the investigator for the purpose of this study. These scales are presented in Appendices D, E & F. Rating reliability was determined by the investigator and another nurse.

Procedures

Parents were approached by the investigator either at the Oncology Clinic in Primary Children's Medical Center or by telephone to ascertain willingness to participate. Parents of subjects in the comparison group were contacted by telephone. Data gathering was completed by one investigator. All families of children with cancer are personally known to the investigator

as she is the Nurse Clinician of the Oncology Clinic where families receive treatment. Explanation of the purpose of the study, the method of gathering information, and the expected time involved was explained in detail to the parents.

Parents were informed they were under no obligation to participate and that they could withdraw at any time without prejudice to them or to their children. Parents were also assured of confidentiality through coding of information to maintain anonymity for the family.

When a parent agreed to participate, an appointment was made for a home visit by the investigator. All home visits were scheduled during the day to attempt to control for the possible effect of the time variable on childhood performance. Written consent was obtained at the time of the home visit (Appendix A).

The maternal interview was completed first, with privacy of the parent maintained as much as possible. After the maternal interview was completed, the investigator administered the Projective Picture Test followed by the General Anxiety Scale to each subject in the family who fit the sibling criteria. As much as possible, privacy was maintained with each subject during the administration of both tests.

After completion of data collection, the investigator inquired about and answered any questions or concerns parents or subjects had regarding the visit and/or information shared.

CHAPTER III

RESULTS AND DISCUSSION

Interjudge Reliability

The two dependent measures, the General Anxiety Scale for Children and the Projective Picture Test were scored by two judges. Since determination of the GASC score required no judgmental decisions, a simple check of computations was done.

Of the 464 Projective Picture Test stories, a total of 184 or 40% of the stories were scored independently by two judges. Percentage of agreement between the pair of judges was defined as the number of agreements on a category divided by the sum of the frequencies possible in the given category. The percentage agreement on decisions as to whether a story was scorable was 97.77%. For identification of expressed anxiety, the lowest percentage of agreement was 93%, the highest, 95%. The overall average interjudge agreement was 94%.

Whenever a discrepancy occured in scoring, the final scores used for statistical analysis were the result of interjudge discussion and agreement. Of the remaining 280 stories, whenever questions arose regarding scoring, the final scores used were again determined by interjudge discussion and agreement.

Of the 25 maternal interviews, six or approximately one-fourth were also read and rated by the same two judges; the remaining 19 were read and rated by the investigator only. Percentage of agreement was determined as above, and interjudge reliability was 83%.

Research Question One

Do subjects, 6 to 10 years of age, whose brother or sister has been diagnosed with cancer, express significantly greater anxiety as measured by the GASC than subjects of a comparison group?

A mean was available for comparison computed from Sarason's original work (1960) with 597 American school children. However, the mean was derived more than twenty years ago, and the societal norms may have changed significantly since the early 60s. Therefore, the comparison group for this study was tested to establish a comparative control mean rather than using Sarason's results.

As noted in Table 2, the means of the two groups were almost identical. The first research question therefore, was not supported.

One possible explanation for this is the type of services offered these oncology families through PCMC Hematology-Oncology Department. The Oncology Team believes strongly in the importance of family involvement and thus from the very beginning, from diagnosis, families are encouraged to include non-ill siblings

Table 2

GASC Means of Combined Sibling Group and Comparison Group

Group	n	GASC Mean	Standard Deviation	Range
Combined Siblings ABD	32	25.906	7.127	6-38
Comparison C	28	26.000	8.585	6-39

as much as possible. The Nurse Clinician and social worker initiate sibling sessions as needed with individual families, and all team members are conscientious about developing rapport with healthy siblings as well as with the patient. This approach provides opportunities to offer education and support to healthy siblings who, as previous studies have shown, frequently experience heightened rivalry, jealousy and feelings of relative deprivation (Maddison & Raphael, 1971; Minde, 1978; Steinhauer et al. 1974).

Another tentative explanation for lack of significant differences between the two groups is the possibility that rather than having processed their experiences well and adapting positively, these siblings may be using adaptive denial so extensively that their anxiety is simply not allowed to surface.

The judgment as to which of these two processes may be operating is beyond the scope of this research. However, although no general psychological adjustment assessment was done with these subjects, if one assumes that increased expression of anxiety may also be reflective of possible psychological adjustment problems, findings of this study are supportive of other recent sibling investigations.

Lavigne and Ryan (1979) compared psychological assessments of siblings of cardiac, hematology-oncology and plastic surgery patients with a control group of healthy siblings. They found no significant differences in terms of overall disturbance or general psychopathology among the four different sibling groups

Combining all groups and all ages did reveal significant sex differences however, which will be reviewed later.

This trend of minimal differences between sibling groups was also identified earlier in a study by Gath (1972) who compared siblings of cleft-palate patients, siblings of patients with Down's Syndrome and siblings of healthy children in a control group. He also found no elevated incidence rates in adjustment problems.

Tew and Lawrence (1973) on the other hand found that siblings of children with spina bifida were four times more likely to show signs of maladjustment in school than siblings of healthy control subjects. The discrepancies between these findings suggest that factors specific to each different disease process may influence the type and degree of effect of illness on healthy sibling's adaptation. Thus, potential generalization of the GASC findings to siblings of other chronic illnesses would not be valid.

Research Question Two

Does anxiety as measured by the GASC vary significantly with changes in the treatment status of the child with cancer?

The results of the GASC scores of the comparison group and the individual sibling groups, categorized relative to the treatment status of the sibling with cancer are presented in Table 3.

Examination of Table 3 indicates no significant difference in mean scores on the GASC between the subjects in Group A

Table 3

GASC Means by Group

Group	n	GASC Mean	Standard Deviation	Range	F. Prob.
A	15	23.200	5.7966	11-35	.0725
B	9	25.000	8.4705	6-34	
D	8	32.000	4.0708	26-38	
C	28	25.906	8.5851	6-39	

(whose siblings were receiving treatment), Group B (whose siblings had completed treatment) and Group C (the comparison group). However, analysis of variance revealed differences significant at the .07 level between Group A and Group D (whose siblings had died from cancer).

The scores within Group D were not normally distributed. The range of 12 points for Group D however was the smallest range of any of the individual groups. It is also interesting to note that the lowest GASC score within Group D was 15 points above the lowest score in Group A and 20 points above the lowest scores in Group B and Group C.

The mean of Group A was the lowest of the individual groups. Scores in this group were not normally distributed, with two-thirds of the scores between 20 and 29, and one extreme score of 35. Although Group B had one extremely low score of 6 points and one score of 19 points, the remaining scores ranged between 24 and 32. The mean of Group B most closely approached the mean of the comparison group (Group C), with the exception of the combined sibling group scores (Group ABD), whose mean was just one-tenth less than the mean for the comparison group.

Examination of these GASC scores relative to specific sibling groups shows significant variance at the .07 level. The second research question therefore, was supported. As noted, Group D siblings, whose brother or sister died from cancer, expressed significantly greater anxiety as measured by the GASC than siblings in Group A, whose brother or sister remained on

treatment. The trauma of loss and bereavement experienced at a time when cognitive and emotional development is limited and in flux creates notable stress for the school-aged child. The result then of Group D siblings expressing the greatest anxiety is not unexpected. Previous studies with families of children who died from cancer have found significant psychological difficulties, behavioral and academic problems in school, and significant incidence of problems related to sleep, enuresis, increased physical complaints and feelings of jealousy, guilt, anger and depression. (Cobb, 1956; Binger et al., 1969; Stehbens & Lascari, 1974; Albin et al. 1971; Kaplan et al., 1976).

An unexpected result of group variance was that siblings of brothers or sisters who were currently receiving treatment expressed the least amount of anxiety. One would have suspected greater rather than lesser anxiety.

A possible explanation, however, for this finding is that families (including the well siblings) coming often to the clinic receive continued support, validation of feelings and opportunities to discuss conflicts in the home arising due to the patient's illness and/or treatment. Positive adaptation can thereby be enhanced through this interaction. Parents, patients and healthy siblings can benefit from such interaction, either directly or through an interactive effect due to family system interdependencies.

The possibility of growth and positive adaptation by siblings was supported in a previous study with siblings of

children with cystic fibrosis. This study found that healthy siblings scored higher than normal children in terms of the averaged total self concept scores (Gayton et al., 1977). Although other factors specific to the genetic component of cystic fibrosis may influence these results, the finding is noteworthy.

Another study, specific to siblings of children with cancer, although very limited in sample size, also revealed evidence of personal growth in areas of self-concept, cognitive understanding, and empathy in healthy siblings (Iles, 1979).

One last group variation worthy of note was the similarity of Group B to Group C. Both the means and the standard deviations were very similar (See Table 3). Noting that once patients have completed treatment, family disruption decreases, one could assume that the healthy sibling's perception of family anxieties would also decrease and his family experience may more closely match those of siblings in the comparison group.

An unexpected, yet potentially significant finding from the use of the GASC in this study was the notably increased group means. The results of the Sarason study (1960) over twenty years ago indicated a mean score of 12 for the group of 597 American school children studied. Even the lowest GASC mean of 25 in this study is greater than double the mean established by Sarason in the original study 20 years ago. Waechter's study (1968) conducted more than 10 years ago did not establish a control mean, but found children with brief and chronic illnesses to

have mean scores of 18 and the fatally ill group to have a mean score of 36.

The generally inflated mean scores of this sibling study may be a function of various factors. First, children today may indeed be more anxious due to multimedia exposure to current events, world affairs and increased portrayals of violence and thus the scores may be reflective of a truly more "anxiety prone" population. Secondly, today's society demands more and demands it earlier of its youth. The push to excel and to "do your own thing" may create greater stress on youngsters who must compete within multi-counter cultures to attain and maintain their own identity. Thirdly, children may simply be more open today about expressing their concerns. (Although the investigator personally knew each of the subjects through association as the nurse from the clinic where the patients were treated, lack of acquaintances did not seem to affect the "willingness to be open" of the comparison group whose subjects were for the most part unknown to the investigator.)

There were two areas of data related to the GASC scores which were significant but were not identified as reaearch questions. A brief analysis of this data follows.

GASC Sex Distribution

Although the sample size was quite small for reliable or valid statistical analysis, notable trends relative to sex distribution between and among the groups were identified.

Examination of the scores by sex distribution indicated that except for the males of Group D, females in each of the individual groups as well as the combined female sibling group (ABD) scored consistently higher on the GASC than the males (See Table 4). Female mean scores ranged between 24.88 and 31.00, whereas male mean scores ranged (with the exception of Group D males with a mean of 33.67) from 22.15 to 24.53. This is similar to both Sarason's (1960) and Waechter's (1968) findings in which females consistently scored higher than males on the GASC measurement. Contrary to this trend is the comparison of Group D males and Group D females, with males scoring slightly higher than the females.

Reviewing the male groups alone, as noted above, Group D males had a significantly higher mean then the other three male groups, which were essentially almost identical. In comparing the combined male sibling group (ABD), with the male comparison group, it was found that male siblings of children with cancer as a group tend to express slightly greater anxiety than male siblings of the comparison group.

Examination of the female means shows Group D females expressing the greatest anxiety as measured by the GASC mean, a trend previously also noted in the male sibling groups. Contrary to the trend seen with the males siblings, however, was the finding of a combined female sibling group (ABD) mean lower than the mean score for females of the comparison group.

Table 4

Sex Distribution of Group Means for GASC

Group	Male n	Female n	Male Mean	Female Mean	Male Median	Female Median	Male S.D.	Female S.D.	Male Range	F. Prob. .029 Female Range
A	6	9	22.167	24.889	24.000	25.000	4.021	6.882	15-25	11-35
B	6	3	22.333	30.333	24.500	31.000	9.092	4.041	6-32	26-34
D	3	5	33.667	31.000	34.000	30.500	3.512	4.416	30-37	26-38
C	13	15	22.154	29.333	22.000	29.00	8.640	7.247	6-35	16-39
ABD	15	17	24.533	27.118	24.875	28.00	7.708	6.566	6-37	11-38

GASC "Vulnerability" Questions

Based on the assumptions that personal experiences with a sibling diagnosed and treated for cancer would potentially create significantly greater anxiety or perceptions of increased personal vulnerability, a sample of nine specific questions relating to personal vulnerability and perceptions of parental vulnerability were selected from the GASC for separate analysis. Scores were tabulated for percent answering "positively" to the nine specific questions, as indicated in Table 5.

Noteworthy is that the siblings whose brother or sister died of cancer expressed significantly greater anxiety as measured by the total percent of responses to the nine specific questions. They expressed more concern than any other group about whether their bodies were growing normally and about whether they were going to get sick. They were also the most fearful of the groups about getting hurt themselves. Interestingly enough, however, they expressed less anxiety than the comparison group regarding concern about "something bad happening" to them personally.

In reference to the specific question concerning "something bad happening," the comparison group expressed much greater concern than any of the sibling groups. Also, compared with the combined sibling group (ABD), a greater percentage of the comparison group expressed concern regarding worries about personally getting sick, about going to the doctor's office, and slightly more about whether their bodies were growing normally. The com-

Table 5

Responses to GASC "Vulnerability" Questions

Group	n	Question 2	Question 6	Question 40	Question 32	Question 18	Question 20	Question 43	Question 10	Question 34	Total Percent
A	15	53%	53%	47%	47%	20%	33%	60%	73%	73%	51%
B	9	44%	78%	22%	11%	67%	67%	44%	78%	67%	53%
D	8	88%	50%	63%	63%	63%	88%	63%	100%	88%	74%
C	28	61%	64%	57%	46%	50%	50%	79%	71%	64%	60%
ABD	32	59%	59%	44%	41%	44%	56%	56%	81%	75%	57%
Total	60	60%	62%	50%	43%	47%	53%	67%	76%	70%	59%

Questions

2. Do you sometimes worry about whether your body is growing the way it should?
6. Do you worry about whether your mother is going to get sick?
40. Do you worry about whether your father is going to get sick?
32. Do you worry that you are going to get sick?
18. Do you ever get worried when you have to go to the doctor's office?
20. Have you ever been afraid of getting hurt?
43. Do you sometimes get the feeling that something bad is going to happen to you?
10. When your father is away from home, do you worry about whether he is going to come back?
34. When your mother is away from home, do you worry about whether she is going to come back?

parison group expressed more concern than the combined sibling group regarding worries about parental illness, but less concern regarding separation from parents and worries about the likelihood of parents returning.

Both the group of subjects with siblings receiving treatment (Group A) and those having completed treatment (Group B) expressed less total percent anxiety than either the combined sibling group or the comparison group. This is partially reflective however of greater variability within each of these groups.

Research Question Three

Do subjects whose brother or sister has been diagnosed with cancer express greater anxiety on the Projective Picture Test (as measured by the Total PPT Anxiety Score) than subjects of the comparison group?

Of the 60 children tested, 58 completed the series of eight pictures. One six year old male of sibling Group A and one ten year old female of Group C became withdrawn and despite prompting and exploration of their feelings they refused to tell the stories. (They both did, however, show curiosity about and complete the GASC Questionnaire.)

Of the 464 Projective Picture Test stories, a total of 184 or 40% of the stories were scored independently be two judges to establish interjudge reliability which was computed at 94%. Stories were scored for types of anxiety expressed, (separation or loss, threat to body integrity, and death), for outcomes of the stories (positive, negative and doubtful),

and for a Total Projective Picture Test Anxiety Score (For the complete scoring system, see Appendix G).

The findings are presented first in terms of analysis of the Total PPT Anxiety Score. Subsequently, the specific anxiety categories and the specific outcome categories are reviewed to identify differences between the groups.

The Total Projective Picture Test Anxiety Score represents the average sum of the presence of any of the three anxiety categories (loss, threat to body integrity, or death), in each of the eight stories plus the presence of negative outcomes expressed in any of the stories. The total sum possible ranged from 0-32 points (i.e. 4 points possible per picture). Actual scores for the groups on this test ranged from 4-19 points. Table 6 presents the mean results of the combined sibling Group (ABD) and the comparison Group.

In regard to the research question concerning anxiety as expressed in the Total PPT Anxiety Scores, no significant differences were found between the combined sibling Group (ABD, n=31) and the comparison group (C ,n=27). Although the difference was not statistically significant the combined sibling group unexpectedly expressed slightly less anxiety than the comparison group of siblings.

Interpretation of these results is difficult. Limited discrimination between the two groups may reflect a variety of possible adaptation processes by the siblings and it may also reflect innumerable other uncontrollable factors. Furthermore,

Table 6

Mean Total PPT Anxiety Scores of Combined Sibling Group and Comparison Group

Group	n	Mean	Standard Deviation	Range
ABD	31	9.323	3.280	4-19
C	27	10.1481	2.8784	5-17

lack of significant differences may in and of itself be significant.

These results may simply represent lack of significant stress on the sibling of the child with cancer, although this is highly unlikely. At the other extreme, lack of increased expression of anxiety in the combined sibling group may represent the siblings' need for control and for denial of anxiety about possible personal vulnerability. Or, as noted earlier in the discussion of the GASC analysis, slightly decreased expression of anxiety may reflect positive adaptation resulting in growth and decreased sensitivity to anxiety cues.

Research Question Four

Does anxiety as measured by the Total PPT Anxiety Score vary significantly with changes in the treatment status of the child with cancer?

Table 7 depicts the results of the means of the Total PPT Anxiety Scores of the individual sibling groups.

In terms of group variation relative to the treatment status of the patient (receiving treatment, completed treatment or dead), analysis of variance revealed no significant differences between the individual groups. The tendency however, of Group D siblings to express greater anxiety than the other two sibling groups is similar to that seen in the GASC analysis and was not unexpected.

The trend of Groups A and B scoring slightly lower than the comparison mean was similar to that seen in the GASC analysis. Previous possible explanations already given to interpret this

Table 7

Mean Total PPT Anxiety Scores by Group

Group	n	Mean	Standard Deviation	Range	F. Prob.
A	14	9.2857	2.4629	6-14	.7453
B	9	9.0000	3.5355	4-15	
D	8	9.7500	4.4960	5-19	
C	27	10.1481	2.8784	5-17	

trend are thus applicable and will not be discussed again here.

Total PPT Anxiety Score and Sex Distribution

As with the GASC data analysis, the Total PPT Anxiety Scores were analyzed for possible trends in sex distribution. Although again sex distributions were not identified as a research question, trends seen are worthy of note.

Table 8 depicts the results of analysis of the Total PPT Anxiety means and their distribution by sex. Comparing males as a group to females, with the exception of Group C females, all male groups expressed greater anxiety than females. Ranges for the Total PPT Anxiety Scores were also slightly higher for males with means between 9.30 and 11.67. The female means ranged between 7.00 and 8.89, except for the comparison female group with a mean of 10.93.

When the sibling Groups A, B and D were combined and compared to group C, it was noted that the combined sibling group males expressed greater anxiety than the combined sibling group females, but the comparison group males expressed less anxiety than the comparison group females.

In comparison of male groups only, Group D males again expressed greatest anxiety of all male groups. Also, the combined male sibling group expressed slightly greater anxiety than the comparison male group. This trend supported that trend seen in the GASC analysis where the combined male sibling group also expressed greater anxiety than the comparison male group.

Review of the female means shows the comparison female group expressing the greatest anxiety with the individual sibling

Table 8

PPT Anxiety Scores and Sex Distribution

Group	Male n	Female n	Male Mean	Female Mean	Male Median	Female Median	Male S.D.	Female S.D.	Male Range	Female Range
A	5	9	10.000	8.889	8.250	9.000	3.240	2.028	7-14	6-12
B	6	3	10.000	7.000	8.500	6.000	3.347	3.606	7-15	4-11
D	3	5	11.667	8.600	10.000	9.750	6.658	2.966	6-19	6-12
C	13	14	9.308	10.929	8.333	10.833	3.250	2.336	5-17	8-17
ABD	14	17	10.357	8.471	8.500	9.000	3.855	2.528	6-19	4-12

female group means all greater than two points below the comparison female group mean. The combined sibling female group thus also scored well below the comparison group female mean.

Anxiety Category Analysis

Each story was examined and scored for expression of three specific anxiety categories and for the type of outcome as outlined in the scoring procedure (See Appendix G). If no anxiety related to the three categories outlined was expressed, the story was scored as non-scorable and not examined further. Stories relating any one or any combination of the three categories of anxiety were scored once only for each of the categories, regardless of the number of times the subject used the designated category. The scores therefore reflect the presence or absence of each anxiety category rather than the total number of times a given anxiety category was used in any of the stories.

Group means were computed for each of the three anxiety categories, reflecting the average number of times the specific anxiety category was used in the series of eight pictures by the subjects of each group. Again, the limited and unequal numbers of subjects in the groups makes analysis tentative at best; however, identification of trends is possible.

Reviewing categorical means generally, all groups expressed greatest anxiety regarding threats to body integrity with means ranging 4.556-5.429. The least amount of anxiety was expressed regarding death, with means ranging between 1.000 and 1.889.

Anxiety about separation or loss fell midway with means ranging 1.444-2.375.

Loss Scores. Analysis of the groups for variance in average loss scores revealed no significant differences among the individual groups. Table 9, however, demonstrates that the mean scores did vary somewhat. Group D again expressed greatest anxiety, with a loss mean of 2.375, indicating that on the average, loss or separation anxiety was expressed in 2.375 of the eight stories. Also, the combined sibling Group (ABD) expressed slightly more loss anxiety than the comparison group. Group B, as in the Total PPT Anxiety Scores, expressed the least anxiety.

Threat to Body Integrity Scores. No significant differences were noted at the .05 level in analysis of variance between the groups regarding the mean scores on expression of threat to body integrity. Examination of Table 10 reveals again, however, trends worthy of note. Except for Group A, with a mean of 5.4286, the comparison group expressed greater anxiety regarding threat to body integrity than the remaining sibling groups and greater than the combined sibling groups. Group B again expressed the least anxiety.

Death Scores. Analysis of variance between the groups revealed no significant differences regarding the subjects' expression of death themes in their stories. Table 11 reveals identical means for Group B and Group C, although the standard deviation was slightly greater in Group B revealing greater

Table 9

Mean Loss Scores by Group

Group	n	Mean	Standard Deviation	Range	F. Prob.
A	14	2.2857	1.5898	0-5	.2601
B	9	1.4444	.8819	0-3	
D	8	2.3750	.9161	1-4	
C	27	1.7407	1.2276	0-5	
ABD	31	2.065	1.289	0-5	

Table 10

Mean Threat to Body Integrity Scores by Group

Group	n	Mean	Standard Deviation	Ranges	F. Prob.
A	14	5.4286	1.2839	3-8	.4717
B	9	4.5556	1.2360	3-6	
D	8	5.1250	1.5526	3-7	
C	27	5.2222	1.2810	3-8	
ABD	31	5.097	1.350	3-8	

Table 11

Mean Death Scores by Group

Group	n	Mean	Standard Deviation	Ranges	F. Prob.
A	14	1.0000	1.2403	0-4	.3550
B	9	1.8889	1.6159	0-5	
D	8	1.7500	2.3146	0-7	
C	27	1.8889	1.4233	0-5	
ABD	31	1.452	1.670	0-7	

variation within this group. Comparing the combined sibling group and the comparison group, it is interesting to note that the comparison group expressed slightly more death themes in their stories than did the combined sibling group.

Discussion of Anxiety Category Results. Knudson and Natterson (1960) attempted to delineate separate and specific categories of threat relative to age. Their research indicated that in their subjects, children under six were mainly concerned with separation, children between the ages of six and ten were more concerned with physical injury, and not until after ten years of age were subjects fearful of their own impending death. They further reported that their findings suggested that these categories of separation, mutilation and death fears were distinct and separate.

Morissey (1966), operating on this premise, also concluded from his studies with children hospitalized because of leukemia, that death anxiety was present largely when subjects were older.

As Waechter (1968) noted however, lack of death anxiety in younger children may simply reflect an inability of previous researchers to utilize the appropriate means to assess anxiety in children. And, as Waechter (1968) surmised, it may also represent displacement of concern with death to concern with threat from without, and concern with loneliness may in actuality be an expression of concern with the ultimate separation of death. Moreover, fears of separation, intrusive procedures and pain may substitute for an underlying general apprehensiveness about survival.

Analysis of specific categories relative to age with subjects for this study revealed no significant differences or trends worthy of note.

Outcome Analysis

Every story which indicated a threat to body integrity or security was scored for the outcome or for the type of ending to the situation described by the subject. Judgments regarding the type of outcome were based on consideration as to the type of resolution of the threat.

Positive outcome was scored if the threat was removed or alleviated whereas negative outcome was scored mainly if the individual identified in the story died or if the individual was in some way worse off at the end of the story. A story was scored as a doubtful outcome if no specific ending was given, if there was an indefinite conclusion to the threat, or if the narrator changed the outcome of the story while telling the story so that the fate of the characters described was dichotomous.

Positive Outcome. The majority of the stories scored for resolution of threatening situations were concluded with positive outcomes by all groups tested. Statistical analysis of variance between the groups revealed an F-Probability of .0416 indicating that the difference in the mean scores was due to something other than chance alone. Examination of Table 12 shows that each of the sibling groups A, B, and D

Table 12

Mean Positive Outcome Scores by Group

Group	n	Mean	Standard Deviation	Ranges	F. Prob
A	14	5.5000	1.7867	2-8	.0416
B	9	4.2222	.9718	3-6	
D	8	4.6250	1.5980	3-7	
C	27	4.1111	1.3681	1-6	
ABD	31	4.903	1.599	2-8	

had a greater proportion of stories with positive endings than did Group C, the comparison group.

Negative Outcome. Analysis of the average proportion of stories ending in a negative outcome revealed a total mean for all groups combined of less than one negative outcome per series of eight stories. Comparison of the groups through analysis of variance was significant at the .07 level. Review of Table 13 shows that Group C, the comparison group, told on the average, significantly more stories with a negative ending than did any of the other groups. Group D on the other hand, told significantly less than any of the other groups.

Doubtful Outcome. In the analysis of each groups' use of doubtful outcome as compared to their use of other outcomes, Groups B and C each expressed doubtful outcomes the least often as compared to expression of either a positive or a negative outcome. Analysis of variance between the groups did not reach significance at the .05 level, however, review of Table 14 shows Group D with a slightly higher mean than any of the other groups and Group B with the lowest mean.

Discussion of Outcome Results. The significant differences noted between the groups on outcome analysis merits brief discussion. The comparison of group differences seen between mean positive outcome scores and mean negative outcome scores is especially noteworthy. With significance at the .04 level, the combined sibling group (ABD) told significantly more stories with positive outcomes than did the comparison group (See Table

Table 13

Mean Negative Outcome Scores by Group

Group	n	Mean	Standard Deviation	Range	F. Prob.
A	14	.5714	.9376	0-3	.0758
B	9	1.0000	1.1180	0-3	
D	8	.5000	1.0690	0-3	
C	27	1.2963	.9121	0-3	
ABD	31	.677	1.013	0-3	

Table 14

Mean Doubtful Outcome Scores by Group

Group	n	Mean	Standard Deviation	Ranges	F. Prob.
A	14	.6429	1.1507	0-4	.5994
B	9	.4444	.8819	0-2	
D	8	1.0000	.9258	0-2	
C	27	.8519	.9074	0-4	
ABD	31	.677	1.013	0-4	

12). In expression of stories with negative outcomes however, with significance at the .07 level, the combined sibling group told significantly fewer stories with negative endings than did the comparison group. The comparison group on the other hand told the greatest number of stories with a negative outcome and the least number of stories with a positive outcome.

Interpretation of these results is difficult at best. Are siblings of children with cancer dealing with their stress by denial and thus determined to make stories end positively and afraid to express negative endings? Does the role of magical thinking seen in younger children influence their need to see only positives and to deny possible negative outcomes? And what of the influence of experience? Those subjects whose sibling had died from cancer expressed the very least number of negative endings in their stories, and were second after Group A in expression of positive endings. Yet there were no significant differences between the groups in the specific anxiety categories, for example, Group D siblings did not express significantly more or less stories with death themes. It becomes obvious that valid interpretation of these results is possible only thru more extensive research and analysis. Greater numbers of subjects must be accumulated before the validity of these results can be accepted.

Research Question Five

Does the Total Anxiety Score as measured by the sum of the

GASC and Total PPT Anxiety Score vary significantly relative to the treatment status of the child with cancer?

The Total Anxiety Score was computed to obtain a measure reflective of overall anxiety expressed by children in the study. In Table 15 is presented the mean scores, standard deviations and ranges for each individual group and the combined sibling group.

Analysis of variance of the Total Anxiety Scores demonstrated significant differences between the individual groups at the .05 level. This finding supported the research question as to whether the subject's expression of total anxiety varied relative to the treatment status of the patient.

Siblings whose brother or sister died from cancer again expressed significantly greater anxiety than any of the other sibling groups. This consistent tendency of Group D siblings to express greater and often greatest anxiety is not unexpected. Reasons for this finding have already been reviewed.

Also demonstrated in the total anxiety analysis, as well as in the GASC results, is the unexpected trend of Group A expressing the least amount of anxiety among the groups. Speculations regarding possible reasons for this trend have also been discussed previously and will not be reviewed again.

Of final importance in discussion of the total anxiety analysis is the close approximation of the combined sibling group mean and the comparison group mean. This was also seen in the GASC analysis and may partially reflect the tendency for differences between individual sibling groups to diminish when sibling groups

Table 15

Total Anxiety Means by Group

Group	n	Mean	S.D.	Range	F. Prob.
A	14	32.375	6.425	18-42	.052
B	9	34.000	8.869	16-45	
D	8	41.750	5.992	31-53	
C	27	35.700	8.231	13-51	
ABD	31	35.258	8.281	16-53	

are combined. This trend seen in both analyses underscores the necessity for discriminative analysis of particular subgroups within the sibling group, otherwise combined sibling results may be misleading.

Total Anxiety and Sex Distribution

As with the previous analyses, group variance in relation to sex distribution was reviewed. Although the sample size was small, computation of variance indicated an F-Probability of .031 for variation of the means according to sex differences (Table 16). With the exception of Group D males, who again expressed the greatest anxiety, the females consistently scored higher than males in each of the individual groups. Examination of Table 16 also indicates comparison group females scoring the second highest mean of both males and females, yet the comparison group males scoring the lowest mean of both males and females.

Comparing individual groups, the comparison group females scored the highest mean just slightly above the mean of Group D females. Group A females scored significantly lower than either of these two groups.

Review of the individual male group means shows noteworthy trends. The mean for Group D, the highest of the male groups was greater than 13 points above the next highest mean of Group B and greater than 10 points above the mean of the combined sibling male group. As noted earlier, males of the comparison group expressed the least amount of anxiety.

Table 16

Sex Distribution of Group Means for Total Anxiety Scores

Group	Male n	Female n	Male Mean	Female Mean	Male Median	Female Median	Male S.D.	Female S.D.	Male Range	Female Range
A	5	9	31.60	32.78	32.00	33.75	5.505	7.345	23-38	18-42
B	6	3	32.33	37.33	33.00	37.00	10.231	7.506	16-45	30-45
D	3	5	45.33	39.60	43.00	41.00	6.807	5.177	40-53	31-44
C	13	14	31.46	39.64	33.00	42.00	9.107	7.355	13-46	26-51
ABD	14	17	34.86	35.59	34.50	37.00	9.437	7.124	16-53	18-45

Research Question Six

Do subjects who have had the opportunity to discuss their concerns and the nature of the patient's illness express less generalized anxiety (as measured by the GASC and Total PPT Anxiety Scores) than subjects who have not had this opportunity?

Previous research of fatally ill children had indicated that they experience and express greater anxiety than chronically ill children despite the fact that they had been given no specific information regarding their disease or prognosis (Waechter, 1968; Spinetta, 1973; 1975). Waechter also found that expression of anxiety decreased in children who had had the opportunity to discuss their illness and prognosis.

Due in part to revealing studies such as those by Waechter and Spinetta, the medical profession has changed its beliefs regarding the pediatric patient's right to information. Health professionals realized that lack of information only created more anxiety in patients, thus families are now encouraged to discuss openly the diagnosis, treatment and prognosis with both the patient and his siblings. Studies concerning the effect of such openess with siblings are, however, lacking.

Social system theorists emphasize the interdependent relationship of family systems, noting that if any part is at risk or in conflict, the whole system is affected. The stress of illness in a child is likely to have great impact on siblings.

The purpose of the following analysis was to determine if, as noted in studies with fatally ill children, the subject's

expression of anxiety varied relative to awareness of the patient's diagnosis, treatment and prognosis. Degree of awareness was partially based on the parents' perception of the amount of parental verbal interaction with the subject regarding these issues, and partially on the parents' subjective opinion regarding the subject's awareness (See Awareness Scale, Appendix D).

In terms of awareness, subjects in this study were for the most part, very well informed regarding the patient's diagnosis, treatment and prognosis. Information regarding the patient's diagnosis and prognosis was purposely witheld from only two subjects, both within the same family.

Two major groups were identified within the combined sibling group by measurements of awareness of the patient's illness. This identification simplified analysis of the potential relationship between awareness and expression of anxiety.

Analysis was performed by grouping subjects who received a score of 6 on the awareness scale (n=9) and subjects who received a score of 7 on the awareness scale (n=21). (The remaining two subjects both scored 3 on the awareness scale, but means were not computed due to the small sample size). Group means were then computed on the GASC and the Total Projective Picture Test Anxiety Score to assess the amount of expressed anxiety. Table 17 displays the results.

In identifying the two different groups, it was noticeable that the majority of the subjects scored 7 on the awareness scale (See Awareness Rating Scale, Appendix D). The remaining 9 subjects

Table 17

Comparison of Awareness with GASC and Total PPT Anxiety Means

Group	n	GASC Mean	Mean Lie Score	Total PPT Mean
Awareness 6	9	21.3333	4.0	
Awareness 7	21	26.5714	3.1	
Awareness 6	9			11.125
Awareness 7	20			9.150

scoring 6 were equally distributed among the sibling groups with three subjects each per group.

The differences between these two groups were minimal and depended basically upon discussion of the patient's prognosis. The subjects were all informed as to diagnosis and treatment, but those scoring 6 were met with some evasiveness by parents regarding the possible final outcome or prognosis.

Examination of Table 17 reveals conflicting results in terms of anxiety expression. The group of subjects with less awareness scored slightly lower on the GASC, but slightly higher on the PPT. This group also however scored slightly higher on the GASC lie score which causes one to question somewhat the reliability of the GASC score for that group (especially since there is a strong negative correlation ($p = .001$) for the combined sibling group between the GASC and the lie score).

Although the computations were not done, analysis utilizing the Total Anxiety Score (the sum of the GASC and Total PPT Anxiety Score) may be more reliable in assessing expression of anxiety and thus may yet demonstrate a significant relationship between awareness and anxiety as has been noted in previous studies (Waechter, 1968).

Research Question Seven

Do mothers perceive a change in the subjects behavior after the diagnosis and/or death of the patient, as measured by the Behavior Change Scale?

Behavior changes were assessed by interviewing mothers about

their perception of changes in the subjects' behavior after the patient was diagnosed. Five major areas of behavior were assessed, these included: 1) the subject's relationship with other non-ill subjects in the home; 2) the subject's health/illness behavior (complaints of headaches, stomachaches, sleeping disturbances); 3) the subject's mood or psychoemotional behavior (irritability, moodiness, whining), 4) the subject's expression of fears; and 5) scholastic behavior (grades, interaction with peers at school). Assessments of mother's perceptions of changes in these areas after the patient died were also undertaken with mothers in group D.

In order to provide as much consistency in maternal ratings as possible, mothers were given a rating scale for Behavior Changes developed by the investigator (See Appendix E). Ratings ranged from one, no change, to five, which was pronounced and persistent change.

Table 18 depicts the results of this assessment, giving the percent of occurrence for each rating in the five areas of behavior assessed. The total number in each of the sibling groups was small, for this reason, percentages for the combined sibling group were also calculated.

As noted in Table 18, mother's perceptions of the behavior changes exhibited by subjects after the diagnosis of cancer in the patient were diversified and intriguing. Because the population was small and varied within groups, and since comparable trends were generally notable among the groups, discussion will be limited to results calculated from the combined sibling group. Following this will be a brief discussion of the difference in Group D

Table 18

Incidence of Behavior Changes

Category of Behavior Changes	Score	Group A (n=15)	Group B (n=5)	Group D (n=7)	Group D $\bar{p}$ death (n=7)	Group ABD (n=27)
Relationship with Non-Ill Siblings	1	60%	80%	57%	57%	63%
	2	40%	20%	29%	14%	35%
	3	---	---	14%	29%	4%
	4	---	---	---	---	---
	5	---	---	---	---	---
			(n=6)	(n=8)	(n=8)	(n=29)
Health/Illness Behavior	1	53%	50%	63%	25%	59%
	2	20%	---	13%	13%	10%
	3	---	---	---	---	---

Table 18 Continued

Category of Behavior Changes	Score	Group A (n=15)	Group B (n=6)	Group D (n=8)	Group D $\bar{p}$ death (n=8)	Group ABD (n=29)
	4	20%	33%	13%	25%	21%
	5	7%	17%	13%	38%	10%
Mood Changes	1	40%	17%	25%	13%	28%
	2	40%	67%	63%	25%	55%
	3	---	---	---	---	---
	4	20%	17%	13%	---	17%
	5	---	---	---	63%	---
Expression of Fears	1	80%	83%	63%	25%	76%
	2	13%	17%	25%	25%	17%
	3	---	---	13%	25%	3%
	4	---	---	---	13%	3%

Table 18 Continued

Category of Behavior Changes	Score	Group A (n=15)	Group B (n=6)	Group D (n=8)	Group D p̄ death (n=8)	Group ABD (n=29)
	5	7%	---	---	13%	3%
				(n=7)		(n=28)
Scholastic Behavior Changes	1	73%	67%	71%	13%	71%
	2	20%	---	29%	38%	19%
	3	---	---	---	---	---
	4	7%	33%	---	50%	11%
	5	---	---	---	---	---

between perceived behavior changes after the diagnosis and after the death of the patient with cancer.

Approximately 40% of the mothers noted mild changes in the subject's relationship with other non-ill siblings in the home. These ranged from "they became much closer" to "they seemed to compete with each other more for awhile."

Health/illness behavior changes were not noticed in approximately 60% of the subjects. However, of the changes reported in this area, approximately 30% of the time the changes were perceived as pronounced. Typical health/illness behavior changes noted were similar to those identified in previous sibling studies (Cobb, 1956; Binger et al., 1969; Stehbens & Lascari, 1974). Changes reported included enuresis, stomachaches, headaches, increased school absence and sleeping disturbances.

Changes in mood were the changes most consistently reported by mothers. Although the majority reported these changes as mild or intermittent, they were significant, being reported 72% of the time. Children exhibiting mood changes were noted to be more irritable, moody, withdrawn and anxious for as long as 6 months after the diagnosis of cancer in the sibling was made. These changes in mood were also similar to those identified in previous studies with siblings of sick children (Binger et al., 1969; Gogan et al., 1977; Lavigne & Ryan, 1979).

The majority of mothers (76%) reported no changes in subjects' expression of fears after the diagnosis of cancer had been made. Of those that did report changes, the majority were noted to be

only mild. Mothers reporting changes in subjects' expression of fears noted that they frequently were related to increased fears of the dark and fearfulness about being alone.

In regard to scholastic behavior changes, the majority of mothers (71%) again reported no notable differences after diagnosis of cancer in the patient. Change noted, though intermittent, tended to be reflected in lower grades and reduced social involvement with peers.

Looking specifically at those subjects whose brother or sister had died from cancer, mothers were asked to rate behavior changes in the areas outlined for two different time periods. Mothers rated degrees of behavior change noted for the time period after diagnosis and for the time period following the death of the child with cancer.

Ratings for behavior changes as perceived by mothers were of course very subjective and certainly influenced by the psychoemotional trauma being experienced by the family during both time periods. This factor limits the validity and reliability of the results.

The amount of time between diagnosis and death varied from one month to two and one-half years, with the average time of eleven months. This variable time factor may also influence the reliability of results in this very small sample.

And lastly, the time interval between the death of the patient and the time of the interview also varied, with the majority (5) of the patients having died between one and two

years prior to the study. Two patients had died between two and three years earlier, and one patient had died approximately nine months prior to the interview.

Despite these variables, noticeable trends were identified. The first area, regarding the subject's relationship with other non-ill siblings showed no significant changes with the majority reporting no changes either after diagnosis or after death.

Health/illness behavior changes were minimal after diagnosis in this group with 63% reporting no changes. Changes in health/illness behavior after the death of the patient however, were pronounced with 75% reporting mild to pronounced changes. Significant within the majority reporting notable changes was that 38% were reported to have pronounced and persistent changes in health/illness behavior. This change was manifested by preoccupation with body processes, expression of greater anxiety and fear over even mild injuries or illnesses and increased frequency of physical complaints generally. Previous studies have also noted these particular changes (Cain et al., 1964; Lascari, 1978; Binger et al., 1969; Kaplan, 1976).

As seen generally, mood changes were the most frequently reported changes seen by mothers for both time periods. Significant to note however, was the difference in the degree of changes seen. Sixty-three percent of the mothers noted mild, intermittent changes after the diagnosis of the patient with cancer, whereas, after the death of the patient, 63% reported pronounced and persistent mood changes and only 25% reported

mild and intermittent mood changes.

Expression of fears also dramatically increased after the death of the patient as compared to after the diagnosis of the patient. Whereas the majority of the mothers, 63%, reported no changes after the diagnosis, 75% of the mothers reported mild to pronounced changes in siblings' expression of fears after the death of the patient. Those reporting increased fears noted that siblings especially expressed increased fears of the dark and increased separation anxiety. This is not unexpected in that these particular fears have been noted to be symbolic to children of death and children's limited cognitive abilities limit adequate understanding of the abstract concept of death (Barnes 1978; Spinetta 1975; Waechter 1968).

The last area of review, scholastic behavior changes, also revealed dramatic differences after the death of the patient. After the diagnosis of the patient with cancer, only 29% reported mild and intermittent scholastic changes. However, after the death of the patient, 88% were reported to exhibit mild to pronounced intermittent scholastic behavior changes. These included those identified in previous studies such as school phobia, drop in grades, withdrawal from peer interaction, and some disciplinary problems (Barnes 1978; Binger et al., 1969; Cain et al., 1964; Furman 1970).

Encouraging in these results was that none of the mothers noted scholastic changes to be persistent, but rather intermittent, closely related to the immediate time period following the death

of the patient.

Research Question Eight

Do subjects who have experienced a death in the immediate family, or who have had other significant death experiences express more anxiety or more death themes than those who have not had this experience?

Determination of the possible relationship between the subjects' previous experiences with serious illness or death and their expression of anxiety was accomplished through Pearson Correlation Coefficient analysis.

Combining the sibling groups, significant correlations were evident. A correlation coefficient of .5015, significant at the .05 level, was found between subjects' experience with death of a sibling and their GASC scores. A positive correlation was also noted (Correlation .4798, p.006) between this same experience and measurement of the Total Anxiety Score which is the sum of the GASC score and the Total Projective Picture Test Anxiety Score. With significance at the .03 level, a correlation of .3934 was noted for the combined sibling group between the Total Anxiety Score and subjects' previous experiences with a severe illness of a significant person close to them, who was critically ill but did not die and recovered normal functioning.

The Family Effect

A family effect is tenable when you expect that members of the same family are similar on a given dependent variable and

that a given family is different from other families.

In order to simplify the statistical analysis, it was decided that the family effect would not be controlled. This required that the statistical tests be based on the assumption that there is no family effect and therefore the sample values are assumed independent.

Since the sample included more than one child from the same family, the assumption of family effect was tested on two variables. The two variables selected, GASC Score and Total PPT Anxiety Score, were believed to be more influenced by family membership than any other variables investigated. If no family effect was observed on these two variables, perhaps no other variable examined was affected by family membership.

Family effect was tested using a maximum likelihood approach to the general mixed model analysis of variance. For the Total Anxiety PPT Score, the likelihood ratio chi-square was statistically significant ($p = .001$). This indicates that differences between the four study groups on this variable could be partly explained by the subjects' family memberships. Stated another way, a child's Total Anxiety PPT Score could be affected by some phenomena related to family experiences. Hence, the family effect was needed as a term in the analysis of variance model for Total Anxiety PPT Score.

For the GASC score, the likelihood ratio chi-square test was not statistically significant ($p=.152$). GASC, then, is probably not strongly influenced by family effect.

The consequence of ignoring a family effect in the statistical analysis is that less confidence can be placed in the p-values of the tests than could be otherwise.

Limitations

The study was limited to a population from the greater Salt Lake Valley and southwestern Idaho. The sample criteria specified siblings, aged 6-10 inclusive, of children diagnosed with cancer and who received treatment through the Oncology Clinic at Primary Children's Medical Center where the investigator functions as an Oncology Nurse Clinician. The limitations of these sample criteria discourage direct generalizations of the findings to siblings of children with cancer treated in other treatment centers, to siblings of children with other disease processes, or to siblings in other geographic locations.

The effect on the reliability of small numbers and unequal numbers in each individual group can only be surmised. Also, the inability to match groups better for sex distribution, number of children per family and ordinal positions of both subjects and patients, influences the reliability of results.

The diagnosis of cancer was not limited to a particular type of cancer and thus intensity, duration and frequency of treatment was not controlled. These differences in treatment could significantly influence the degree of family disruption and thus contribute to varying degrees of anxiety experienced by healthy siblings.

The study may also have been limited due to the majority of the sample being predominantly of one religious affiliation which strongly advocates and supports family unity. This supportive influence may have resulted in a higher degree of anxiety resolution thus limiting the expression of anxiety by subjects.

There is one major factor that is difficult to evaluate as to whether it acted as a limitation or an advantage. This factor was the investigator's personal acquaintance with each of the sibling subjects. The investigator had varying degrees of rapport with the sibling sample due to her role as the Nurse Clinician where their brother or sister was treated for cancer. It is difficult to assess the impact or influence of this factor upon the siblings' responses. It may have enhanced their trust and thus allowed them to be more honest in their GASC responses and less inhibited in their imaginary stories, or, it may have limited their openess and spontainiety due to their need to "impress the nurse."

(Although the validity and reliability of the GASC lie score as an indicator of siblings' honesty may be questionable, it is a positive indicator that the difference between the mean lie score of the combined sibling group and the comparison group was less than .05).

In conclusion, one last potential limitation must be discussed which pertains to the investigator's professional association with the patients and their families. This association

may have prompted siblings' memory associations of the investigator with the hospital and the illness of the brother or sister. This is again very difficult to measure. However, although the validity and reliability of the average number of nonscorable stories as a reflection of illness associations and sensitivity to possible anxiety cues may also be questionable, the combined sibling group mean for nonscorable stories was less than .14 greater than the mean for the comparison group.

CHAPTER IV

SUMMARY AND RECOMMENDATIONS

The purpose of this study was to assess the anxieties that school-age siblings of children with cancer experience and to explore the variables suspected to affect the amount and type of anxiety expressed. It was patterned after similar research by Waechter (1968), which assessed anxiety in school-age patients of varying levels of wellness (acutely ill, chronically ill, fatally ill, and healthy children).

Two measures were utilized to assess expressed anxiety expressed by each child. The General Anxiety Scale for children developed by Sarason and his associates (Sarason, Davidson, Lighthall, Waite & Ruebush, 1960) was used to measure expressed anxiety in many areas of living. A modification of the Thematic Apperception Test used by Waechter (1968) was utilized to measure anxiety regarding current and/or future body integrity. A maternal interview was completed to elicit information regarding parental perceptions of subjects' behavior changes after the diagnosis and/or death of the patient with cancer and to assess each subjects' previous and current experiences regarding illness and/or death.

The sampling consisted of 32 healthy children between the ages of 6 and 10 years inclusive whose brother or sister had been treated for cancer within the previous 3 years. This group of subjects was divided into three groups according to the treatment status of the child with cancer, the patient (Group A: patient receiving cancer treatment; Group B: completed treatment; Group D: died of cancer). A group of 28 healthy children between 6 and 10 years of age inclusive, who had not experienced a chronic or life threatening illness within their family and whose brother and/or sisters were currently healthy were also tested to represent a comparison group.

Analysis of the results of the General Anxiety Scale revealed no significant differences between the combined sibling group in which a brother or sister had been diagnosed and treated for cancer and the comparison group. Differences did approach significance, however, (F. Prob. .029) when these two groups were analyzed for GASC results and sex distribution. Both female groups scored significantly higher than males in either group. Males in the combined sibling group scored significantly higher than the comparison male group, yet females in the combined sibling group scored significantly lower than the comparison female group.

Evaluating GASC results relative to the treatment status of the child with cancer showed that those siblings whose brother or sister had died expressed significantly greater anxiety (F. Prob. .07) than any of the other individual groups. The

other two subject groups, however, expressed no greater anxiety than the comparison group.

Analysis of sex distribution and individual group GASC scores revealed that both males and females whose sibling had died expressed the greatest amount of anxiety (F. Prob. .029). Also, with the exception of the males of this group who scored the very highest GASC mean, females of all four groups consistently scored higher than males.

As in the GASC analysis of the combined sibling group compared with the comparison group, analysis of the Total Projective Picture Test Anxiety Scores revealed no significant differences between the two groups.

Examination of the Total PPT Anxiety Scores and sex distribution again showed the combined sibling group males expressing slightly more anxiety than the comparison group males and the combined sibling group females expressing significantly less anxiety than the comparison group females. The females of the comparison group in fact expressed the greatest amount of anxiety on this test score.

Reviewing Total PPT Anxiety Scores of the individual sibling groups and the comparison group showed no significant differences among the groups. Differences were seen, however, when scores were analyzed related to sex distribution among the individual groups. Males, whose brother or sister had died, again scored the highest, females of this group, however, expressed almost the least amount of anxiety. With the exception of the comparison

group females who scored the highest, and contrary to the findings with the GASC, males consistently scored higher than the females on this measurement.

Categorical scoring of the Projective Picture Test showed that the combined sibling group, in which a brother or sister had been diagnosed and treated for cancer, told significantly greater numbers of stories with positive outcomes than the comparison group (F. Prob. .04). They told significantly fewer stories, however, ending in a negative outcome (F. Prob. .07). There were no significant differences among the groups in use of doubtful outcomes, nonscorable stories or in use of loss, mutilation or death themes in the stories told.

Combining the GASC and the Total PPT anxiety Scores for an overall Total Anxiety Score revealed significant differences (F. Prob. .05) among the groups. Although the differences between the combined sibling group scores and the comparison group scores were negligible; significant differences were noted among the four individual groups. The group of children whose brother or sister had died from cancer expressed significantly greater anxiety than the other groups. It is interesting to note however, that those children whose sibling remained in continuous remission, either receiving treatment or having completed treatment, expressed less Total Anxiety than the comparison group.

Distribution of Total Anxiety Scores relative to sex distribution approached significance with an F-Probability of .03. Reviewing scores of the combined sibling group and the

comparison group, females in both groups scored higher than the males in both groups. Also, as was seen in the GASC sex distribution, the comparison group females expressed the greatest amount of anxiety among these groups and comparison males expressed the least amount of anxiety.

Analysis of sex distribution and Total Anxiety Scores for the individual sibling groups which were differentiated by the treatment status of the patient with cancer also revealed significant differences. Consistent with sex distribution in the GASC and the Total PPT Anxiety Scores, males whose sibling had died expressed the greatest amount of anxiety on the Total Anxiety Score. Other than this group of male subjects however, female groups consistently scored higher than all other male groups.

In an attempt to identify factors which may influence anxiety, an analysis of possible correlation was done between the subjects' awareness of the patient's illness and the amount of anxiety subjects expressed. Evaluation of awareness was based on parents' perception of the amount of parental verbal interaction regarding the illness with the subject and on parents opinion regarding the subjects understanding of information regarding the patient's illness. An assessment of parents' perceptions revealed a definite trend toward parental openess and honesty with both sibling subjects and patients.

Analysis of GASC and Total PPT Anxiety Scores relative to awareness revealed conflicting results. No significant differences

were found, however those subjects with less awareness scored slightly higher on the Total PPT Anxiety Score but slightly lower on the GASC.

Analysis of subjects' previous experiences with death was also analyzed to assess possible influence on anxiety. Subjects who experienced the death of a sibling showed significant positive correlation with the Total Anxiety Scores and with the GASC scores. No other significant correlations were noted among the individual groups and measures of anxiety.

Analysis of mother's perceptions of subjects' behavior changes after the diagnosis of the patient with cancer revealed only mild to moderate intermittent changes in most areas analyzed. An exception to this was in the area of mood changes in which 72% of the subjects were reported to have exhibited mild to pronounced intermittent mood changes after the diagnosis of the patient with cancer. Changes in mood were noted to include increased irritability, crying easily, withdrawn behavior and simply increased generalized moodiness.

Significant behavior changes in all areas except one were reported by mothers after the death of the patient. Subjects were reported to exhibit behavior changes a minimum of 75% of the time in all areas except in the area of relationships with non-ill siblings which reportedly changed only 43% of the time after the death of the patient.

Changes in mood were the most significant changes noted by mothers, with 63% reporting pronounced and persistent mood

changes after the death of the patient, and 25% reporting mild and intermittent mood changes. Also significant were changes in scholastic behavior, health illness behavior, and expression of fears.

These findings suggest that as a combined group, siblings of children with cancer do not express significantly greater amounts of anxiety than children in the comparison population. However, when these same siblings are categorized according to the treatment status of the child with cancer, significant differences are notable. Whereas siblings of children currently receiving or having completed treatment for cancer do not express greater anxiety, those siblings of children who have died from cancer exhibit a trend towards greater amounts of anxiety expression. Males of this group appeared to be particularly vulnerable, expressing significantly greater anxiety on each of the anxiety measurement tools.

Interpretation of these results is difficult. All patient families in this study were treated through the Primary Children's Medical Center Hematology-Oncology Department which believes stongly in family involvement. From the time of diagnosis, non-ill siblings are included by all team members who are each conscientious about developing rapport with all family members involved. This approach consistently offered to families, who due to intensive cancer treatment are frequently seen by the Oncology team, offers all family members continued support, validation of feelings and opportunities to discuss conflict in

the home. This interaction may have decreased the anxiety experienced by family members and may have enhanced positive adaptation.

These findings support previous research reports which indicated the therapeutic effectiveness of open, honest communication with children regarding their fears, questions and concerns about illness and threats to body integrity including discussion of life and death issues.

Nursing Implications

The results of this study have implications for nursing care for families with children with cancer as well as for families with children with other health problems. Despite the trend towards family-centered care, non-ill siblings are often ignored. The importance however, can no longer be overlooked of including non-ill siblings in discussions regarding the diagnosis and nature of the illness, the ramifications of treatment, and the prognosis. Nurses as well as parents must be educated regarding this vital issue.

Trends noted in this study also emphasize necessity for follow-up support, especially for male siblings, after the death of a child. Although recent trends in health care have promoted openess and discussion regarding death and dying and adaptation to loss, the importance of follow-up care for families after the death of a child has received minimal attention.

Also worthy of note is the importance of an initial assess-

ment regarding siblings' previous experiences with death. Significant death experiences are noted to influence the amount of anxiety siblings express, and thus if identified initially, they may assist health care personnel to focus on those siblings who are at greater potential risk for anxiety.

Lastly, nurses must be made aware of "typical" behavior changes siblings experience after the diagnosis of a life-threatening illness and after the death of a child in the family. With this information, nurses can assess sibling adaptation more specifically and provide more appropriate anticipatory guidance and counseling for parents who frequently become somewhat blind to non-ill siblings' behavior or needs during the course of the illness.

Recommendations for Future Research

Although significant differences noted from this study were limited, differences and trends of behavior identified are important and merit further research. In order to improve the validity and reliability of both trends and differences noted, it would be important to duplicate this study (or a portion thereof) using (1) a population from other treatment centers which may not have ongoing sibling support programs, and/or (2) using an investigator who is not a member of the health team caring for the patient and who does not know the families. It would also be useful to continue data collection to enlarge the sample population to improve the reliability and validity of research results. With a larger sample, it may also be

possible to identify common factors which could help identify those children at greater risk and needing more support with specific intervention (factors such as sex, ordinal position of patient and sibling, number of children in the family, age, time from diagnosis, etc.).

Also useful would be a comparative study evaluating anxieties in siblings of patients grouped by specific malignant disease process (i.e., Wilms Tumor vs. leukemia vs. Ewings Sarcoma). Such a study could provide information regarding how the intensity and duration of treatment or prognosis may affect anxieties experienced and expressed by siblings. Comparative research would also prove valuable evaluating siblings of other serious, chronic illnesses of childhood.

And lastly, comparative research with a paired population of school-age patients and siblings in each family (similar to the study by Cairns et al., 1979) could provide information regarding family processes as well as similarities and/or differences between sibling and patient anxieties and adaptation processes.

Information gained from any of these suggested studies could assist health professionals to gain better understanding of family and sibling anxieties and adaptation processes and to identify factors influencing adaptation. With this information, health professionals could then identify appropriate intervention to assist the whole family in their adaptation to living with a potentially life-threatening, potentially curable illness.

APPENDIX A

PARENT CONSENT FORM

You and your child are invited to participate in a research project being conducted to assess the anxieties experienced by siblings of children diagnosed with cancer. This project is being conducted by Marcia Nobis, RN, to gain information that will assist health professionals to understand the anxieties siblings experience and to determine if the amount or type or anxiety expressed varies relative to the treatment status of the child with cancer.

The study requires parental participation in the form of a brief parental interview and parental consent to allow siblings to respond to the General Anxiety Scale for Children and the Projective Picture Test adapted for this study. Both the parental interview and stories told in response to the Projective Picture Test will be tape recorded to use later for evaluation in this study and possible educational purposes. In the unlikely event that your child experiences increased anxiety or behavioral problems following the questionnaire and pictures, counseling assistance is available through the Oncology Department, Primary Children's Medical Center. In case of such an occurrance, please contact Marcia Nobis at the Oncology Department.

Your decision to participate or not to participate in the project will in no way influence the medical care you are receiving. Should you agree to participate, you are free to stop the recorder at any point or to withdraw from the project at any time without prejudice. All information received will be kept strictly confidential through a coding process and anonymity for individuals within your family will be maintained if information is distributed in any way.

AUTHORIZATION: I have read the above and agree to the participation of

_____

_____

_____

(name or names of children)

in the project described above. Its general purpose and potential benefits have been explained to my satisfaction.

_____

(Signature)

_____

(Date)

Parent Consent Form
For Control Group

You and your child are invited to participate in a research project being conducted to assess the anxieties experienced by siblings of children diagnosed with cancer. This project is being conducted by Marcia Nobis, RN, to gain information that will assist health professionals to understand the anxieties siblings experience and to determine if the amount or type of anxiety expressed varies relative to the treatment status of child with cancer.

In order to obtain more complete and valid information for this study, a comparison group of normal children whose brothers and/or sisters are healthy must be utilized. You and your child are invited to participate as subjects in this comparison group.

The study requires parental participation in the form of a brief parental interview and parental consent to allow siblings to respond to the General Anxiety Scale for Children and the Projective Picture Test adapted for this study. Both the parental interview and stories told in response to the Projective Picture Test will be tape recorded to use later for evaluation in this study and possible educational purposes. In the unlikely event that your child experiences increased anxiety or behavioral problems following the questionnaire and pictures, counseling is available through the Oncology Department, Primary Children's Medical Center. In case of such an occurrance, please contact Marcia Nobis at the Oncology Department.

Should you agree to participate, you are free to stop the recorder at any point or to withdraw from the project at any time without prejudice. All information received will be kept strictly confidential through a coding process and anonymity for individuals within your family will be maintained if information is distributed in any way.

AUTHORIZATION: I have read the above and agree to the participation of

_____

_____

_____

(Name or names of children)

in the project described above. Its general purposes and potential benefits have been explained to my satisfaction.

_____

(Signature)

_____

(Date)

APPENDIX B

THE GENERAL ANXIETY SCALE FOR CHILDREN

Name_____

The General Anxiety Scale for Children

1. When you are away from home, do you worry about what might be happening at home?
2. Do you sometimes worry about whether your body is growing the way it should?
3. Are you afraid of mice or rats?
4. Do you ever worry about knowing your lessons?
5. If you were to climb a ladder, would you worry about falling off it?
6. Do you worry about whether your mother is going to get sick?
7. Do you get scared when you have to walk home alone at night?
8. Do you ever worry about what other people think of you?
9. Do you get a funny feeling when you see blood?
10. When your father is away from home, do you worry about whether he is going to come back?
11. Are you frightened by lightning and thunderstorms?
12. Do you ever worry that you won't be able to do something you want to do?
13. When you go to the dentist, do you worry that he will hurt you?
14. Are you afraid of things like snakes?
15. When you are in bed at night trying to go to sleep, do you often find that you are worrying about something?
16. When you were younger, were you ever scared of anything?
17. Are you sometimes frightened when looking down from high places?
18. Do you ever get worried when you have to go the doctor's office?
19. Do some of the stories on radio or television scare you?
20. Have you ever been afraid of getting hurt?
21. When you are home alone and someone knocks on the door, do you get a worried feeling?
22. Do you get a scary feeling when you see a dead animal?
23. Do you think you worry more than other boys and girls?
24. Do you worry that you might get hurt in some accident?
25. Has anyone ever been able to scare you?
26. Are you afraid of things like guns?
27. Without knowing why, do you sometimes get a funny feeling in your stomach?
28. Are you afraid of being bitten or hurt by a dog?
29. Do you ever worry about something bad happening to someone you know?
30. Do you worry when you are home alone at night?
31. Are you afraid of being too near fireworks because of their exploding?
32. Do you worry that you are going to get sick?
33. Are you ever unhappy?
34. When your mother is away from home, do you worry about whether she is going to come back?

Name_____

The General Anxiety Scale for Children
(continued)

35. Are you afraid to dive into the water because you might get hurt?
36. Do you get a funny feeling when you touch something that has a real sharp edge?
37. Do you ever worry about what is going to happen?
38. Do you get scared when you have to go into a dark room?
39. Do you dislike getting in fights because you worry about getting hurt in them?
40. Do you worry about whether your father is going to get sick?
41. Have you ever had a scary dream?
42. Are you afraid of spiders?
43. Do you sometimes get the feeling that something bad is going to happen to you?
44. When you are alone in a room and you hear a strange noise, do you get a frightened feeling?
45. Do you ever worry?

Reprinted with permission of the authors. Sarason, S.B., Lighthall, F.F., Davidson, K.S., Waite, R.R., & Ruebush, B.K. Anxiety in elementary school children (Science Editions). New York: John Wiley and Sons, Inc., 1960.

APPENDIX C

PARENTAL INTERVIEW

Background Information

1a. First I'd like to get a picture of the family. How many children do you have?

1b. How old are they? Could you start with the oldest and tell me the name and birthdate of each?

1._____ 5._____

2._____ 6._____

3._____ 7._____

4._____ 8._____

2a. Has _____(sib) been with you all of his/her life, or have you, his/her mother/father been separated from him/her at any time?

1. Separated 2. Never separated

If separated:

2b. How many times were you separated?

1 2 3 4 5 6 or more

2c. How long were you separated the longest time?

____days____weeks_____months_____years

2d. How old was_____then?

3a. And how about his/her father? Has _____been separated from his/her father at any time?

1. Separated 2, Never separated (Skip to question 4)

If separated:

3b. How many times were they separated?

1 2 3 4 5 6 or more

3c. How long were they separated the longest time?

_____days_____weeks_____months_____years

3d. How old was_____then?

Sibling Relationships

4a. Would you tell me something about how_____ and his sibling with cancer get/got along?

Parental Interview (continued)

4b. How did their relationship change after_____'s diagnosis? (Non-ill sibling and child with cancer)

Rating: 1 2 3 4 5

4c. What sorts of things do/did they like to do together?

4d. All brothers and sisters quarrel of course. How are/were _____(non-ill sibling) and _____ (child with cancer) about this?

1. Before diagnosis? 2. After diagnosis

Rating: 1 2 3 4 5

4e. How does_____(non-ill sibling) get along with the other children?

4f. Has their relationship changed since_____'s diagnosis? (Non-ill sibling and other non-ill sibs)

If so, how?

Rating: 1 2 3 4 5

Non-Ill Sibling's Health and Behavior

5a. How would you describe _____'s general health?

5b. Has this changed since_____'s diagnosis? If so, how? (i.e., increased complaints of discomfort, increased school absence due to illness? changes in eating habits? sleeping habits? etc)

6a. Could you give me your opinion about_____'s mood generally?

6b. Has this changed any do you think since_____'s diagnosis? (death?)

If so, how? (i.e., more whiney? clinging? irritable? etc.)

How much? Occasionally? Pronounced but intermittent? Pronounced and consistent?

Parental Interview (continued)

Non-Ill Sibling's Health and Behavior (cont.)

6c. If mood changes are noticeable, can you identify what is generally happening when you notice this? (i.e., treatment week? hospitalization of child with cancer?)

7a. Now I'd like to talk a little about some of the things that frighten children. All children are afraid of some things, of course. Could you tell me about some of the things that frighten_____?

7b. What seemed to frighten him/her when he/she was younger?

7c. What seemed to be his/her behavior? How did he/she show that he/she was scared?

7d. Sometimes these things that frighten children when they are younger stay with them. Has anything in particular stayed with_____?

7e. Has _____'s expression of fears changed since_____'s diagnosis?

Rating: 1 2 3 4 5

8a. And now I'd like to know something about_____'s school life. How does he/she generally do in school?

8b. Does he/she seem to enjoy school?

8c. Has his/her behavior in school changed since_____'s diagnosis? (death?) If so, how? (i.e., scholastic behavior changes? social interactions changes?)

If so, how would you rate these changes?

Rating: 1 2 3 4 5

Parental Interview (continued)

Child with Cancer

Now I'd like to change the subject and talk about_____'s health history.

9a. First, can you tell me when_____was diagnosed?

9b. How long was he/she in the hospital the first time?

9c. About how long was he/she sick before he/she was diagnosed?

9d. Has he/she been hospitalized at other times?

1. No 2. Yes

If yes, tell me about the other hospitalizations.
When?
How long?
For what purpose?

9e. Can you tell me about_____'s treatments?

How often are/were they?
How does/did he/she tolerate them?

10a. What is _____'s current health status?

1. On treatment (how long_____?)

2. Off treatment (how long_____?)

3. Relapsed (when_____?)

4. Dead (when_____?)

Reactions to Hospitalization, Illness and Death

11a. Parents prepare their children for coming into the hospital in different ways. Could you tell me about the ways you used with_____(child with cancer) and_____(non-ill sibling) for the hospitalization of_____(child with cancer)?

11b. Almost all children worry some about hospitalization even with the best of preparation. Did _____(child with cancer) or_____(non-ill sibling) seem to give any in-

Parental Interview (continued)

dications of the particular things that seem to worry him/her?

If so, how?

What about?

If rehospitalized, answer 11c; if not proceed to question 12.

11c. Sometimes when children have been in a hospital before, it helps because they know what to expect. Sometimes, though, it makes it harder to go again. How do you think _____(child with cancer) felt about this?

1. Harder 2. Easier

If harder, in what ways? If easier, in what ways?

What was it like for_____(non-ill sibling)?

1. Harder 2. Easier

If harder, in what ways? If easier, in what ways?

12a. Some parents feel children should know about their illness and others feel that children should be spared this knowledge. How have you handled this?

With the child with cancer?

With the non-ill sibling?

12b. Does _____(non-ill sibling) ask you any specific questions about it or does he/she leave it pretty much up to you?

1. Asks 2. Doesn't ask

If he/she asks:

How do you handle this?

Does he/she seem to ask these questions at different times? If so, when?

Has this changed any during the course of_____'s treatment?

Parental Interview (continued)

14a. Some children have learned more about illness and loss than others. Some parents feel their children should be spared these experiences. Others feel their children should learn about them. How do you feel about this?

14b. What kind of experiences has_____(non-ill sibling) had being around someone seriously ill in the immediate family?

14c. Has _____(non-ill sibling) lost someone he/she was very fond of?

1. Yes 2. No

If yes, what did you do?

How did he/she handle this?

15a. What kind of experience have you and/or your husband had being around someone seriously ill?

15b. Have you or your husband lost someone close to you?

1. Yes 2. No

If yes, who?

16. Parents often have to face the problem of taking their child to the funeral of someone they have known. What have you done about this?

17. When someone in the family has been sick for a long time, it seems to be the hardest for the mother, especially when there are other children to care for. How much of a problem has this been for you and your family?

18. Has_____(child with cancer) needed a great deal of your time and attention at home?

19. How has this worked out for the rest of your family?

APPENDIX D

AWARENESS RATING SCALE

Score	Description
1.	Subject has been told nothing about the patient's diagnosis or prognosis, and has asked no direct questions. Parents and medical staff have actively avoided disclosure of nature of illness, have given misinformation about purpose of treatment. No discussion with the subject.
2.	Subject has asked some direct questions about patient's illness and purpose of treatment, but given seriously incomplete or misleading information. Prognosis kept from the subject, information given that illness is trivial; nature of treatment disguised. Discussion with subject as above.
3.	Prognosis and diagnosis of patient kept from the subject; treatment aspect of illness discussed with subject, some realistic information regarding treatment procedures given. No attempt to discuss illness with subject.
4.	No information given regarding prognosis or diagnosis of patient, treatments aspects of illness discussed more fully with subject; some indication given to subject as to chronic aspect of illness--projection into future.
5.	No direct information given regarding prognosis or diagnosis of patient; subject asks questions regarding illness; attempts made to discuss these with him at the time they arise. Information given as to chronicity of disease.
6.	Diagnosis of patient given to subject (subject may or may not be aware of implications of diagnosis); no direct statement as to prognosis; questions as to illness and treatment discussed as they arise. Subject may or may not question final outcome, but met with some evasiveness.
7.	Prognosis, diagnosis and treatment aspects of patient's illness discussed fully with subject. Subject is aware of nature of illness, treatment aspects, possible or probable fatal outcome, or subject is aware of fatal outcome of others with same diagnosis. Subject asks questions, full attempt made to discuss these when they arise. No effort made to suppress information from the subject.

APPENDIX E

RATING SCALE FOR PARENTAL PERCEPTION OF BEHAVIOR CHANGES

Score	Description
1.	No behavior changes as perceived by parent.
2.	Mild and intermittent behavior changes as perceived by parent.
3.	Mild and consistent behavior changes as perceived by parent.
4.	Pronounced and intermittent behavior changes as perceived by parent.
5.	Pronounced and persistent behavior changes as perceived by parent.

APPENDIX F

PREVIOUS EXPERIENCE WITH SEVERE ILLNESS OR DEATH

Score	Description
1	Subject is currently experiencing relationship with significant person who is currently seriously ill with threat of death, but who has not died. Person may or may not be related to subject.
2	Subject has experienced death in the immediate nuclear family circle when of an age of awareness (i.e., father, mother, sibling). The death experience was profoundly significant.
3	Subject has experienced death of non-nuclear family members or other significant persons of whom he was very fond and with whom he interacted frequently on a regular basis (i.e., grandparent or members of paternal or maternal extended family; close friend, neighbor, etc.). Death occurred at age of awareness.
4	Subject has experienced severe illness of significant person close to him with threat and fear of death known, although person recovered.
5	Subject has peripheral experience with death of someone he has known or relative of someone he has known, or someone he has heard about. Subject has limited or no emotional involvement with deceased, but has shown interest in death with questioning.

APPENDIX G

PROJECTIVE PICTURE TEST SCORING

The scoring system is based on types of anxiety expressed through imagery or imaginary stories told by the subjects. Stories are analyzed to determine the specific types of anxiety expressed by the subjects, the sum total of anxiety, and the outcomes or endings to the situations described in the imaginative stories.

Threats to security or anxieties expressed are scored relative to three different types of anxiety with which children deal when they are ill as identified by Natterson and Knudsen (1960).

Each story is scored separately for imagery concerned with anxiety relating to: 1) separation or loneliness, 2) threat to body integrity (physical illness or body intrusion) and 3) imagery related to death. If the story contains unrelated imagery only, with no discussion of the categories or types of anxieties mentioned above, the story is scored "0" and not examined further.

Threat-related stories are scored once for each anxiety category appearing in the story regardless of the number of times the subject employed the designated category. Thus the score reflects the presence or absence of specific imagery rather than the total number of times a given type of imagery was used in any of the eight stories.

Stories must contain reference to threat to body integrity or to physical or psychological security (loneliness) to be scored. A direct statement of fear about internal or external

threat, or a statement about threat to security is sufficient to score the story. All imagery is scored from the viewpoint of the threatened individual. Stories related to threat of or to actual harm to animals are to be scored. Negative affective states such as sadness, unrelated to loneliness or body integrity is not sufficient to score the story.

Criteria for scoring in the specific categories is as follows:

Types of Anxiety

Separation or loneliness:

The story must contain reference to separation from significant others or feelings of loneliness.

EXAMPLES: "She's thinking she's lost."
"Her mom and dad are gone."
"He's all alone and he feels sad."
"She's locked out of her house and can't get in."
"They moved without her."

Threat to body integrity (physical illness or body intrusion):

Someone in the story is threatened by disease from within or by environmental threat to body intactness.

EXAMPLES: "The girl is very sick."
"He got shot in his belly."
"The house burned but he got out."
"He's having an operation."
"He has to have a shot."

"He got hit and broke his leg."

Death: The story must contain specific reference to death or dying, but outcome will not influence scoring in this category.

EXAMPLE: "They thought he would die, but he got better."

Outcome

Every story which indicated threat to security or to body is scored also for the outcome. Analysis of the outcome or the ending to the situation described in the imaginative stories is separated into three categories as follows:

Positive Outcome:

This outcome is based on considerations as to whether the threat was alleviated or removed. The threatened individual in the story gets well, goes home from the hospital, successfully avoids an accident or body mutilation, or experiences relief from loneliness. There is a positive end to the story.

EXAMPLES: "It ends happy, he got well."

"His dad gets better and gets to go home."

"She gets her tonsils out and her parents came and took her home."

Negative Outcome:

This outcome is determined mainly if the individual in the story dies or if there is an indefinite prolongation of threat.

There is a negative ending to the story. Internal or external forces continue at work which will result in the person being worse off in the future.

EXAMPLES: "He's worried if he'll get shot too, and and he does and he dies."

"At night he was killed, somebody stabbed him."

"She had to be in a wheelchair the rest of her life."

Doubtful Outcome:

If there is no certain ending to the story, the outcome is scored doubtful. There may be statements of uncertainty or ignorance as to whether the character in the story maintains or regains body integority, whether he can go home from the hospital, or whether he ever gets well. Doubtful outcome will also be scored if the narrator changes the outcome of the story while telling the story from the viewpoint of the threatened individual.

EXAMPLES: "She hopes she would find her."

"He fell on a stick and died. But then he came back to life."

"She's wondering about whether she'll wake up (be alive) when morning comes."

"They're wondering if they'll come back."

"They're very worried."

SELECTED BIBLIOGRAPHY

Abram, S. The psychology of chronic illness. Journal of Chronic Disease, 1972, 25, 659-664.

Albin, A.R., Binger, C.M., Stein, R.C., Kushner, J.H., Zoger, C. & Mikkelson, C. A conference with the family of a leukemic child. American Journal of Diseases of Children, Oct. 1971, 122, 362-364.

Barnes, M.J. The reactions of children and adolescents to the death of a parent or sibling. In. O. Shaler (Ed.), The child and death. St. Louis: C.V. Mosby Co., 1978, pp. 185-201.

Berman, L.E. Sibling loss as an organizer of unconscious guilt: a case study. Psychology Quarterly, 1978, 47, 568-587.

Binger, C.M., Albin, A.R., Feuerstein, R.C., Kushner, J.H., Zoger, S. & Mikkelson, C. Childhood leukemia: emotional impact on patient and family. New England Journal of Medicine, February 20, 1969, 280 (8), 414-418.

Binger, C.B. Childhood leukemia--emotional impact on siblings. In E.J. Anthony and C. Koupernik (Eds.), The child in his family (Vol. II). New York: John Wiley and Sons, 1973, pp. 195-209.

Bowlby, J. Childhood mourning and its implications for psychiatry. American Journal of Psychiatry, December 1961, 118, 481-498.

Cain, A.C., Fast, I., & Erickson, M. Children's disturbed reactions to the death of a sibling. American Journal of Orthopsychiatry, 1964, 34, 741-752.

Cairns, N.U., Clark, G.M., Smith, S.D., & Lansky, S.B. Adaptaof siblings to childhood malignancy. Journal of Pediatrics, September 1979, 95 (3), 484-487.

Cobb, B. Psychological impact of long illness and death of a child on the family circle. Journal of Pediatrics,

Coddington, R.D. The significance of life events as etiologic factors in the diseases of children. Journal of Psychosomatic Research, 1972, 16, 7-18.

Dubos, R. Mirage of health. New York: Perennial Library, Harper & Row Publishers, 1959.

Everson, S. Sibling counseling. American Journal of Nursing, April 1977, 644-647.

Feinberg, D. Preventive therapy with siblings of a dying child. Journal of the Academy of Child Psychiatry, 1970, 9, 664-669.

Ferguson, G. Statistical analysis in psychology and education (4th ed.). New York: McGraw Hill Book Company, 1976.

Findley, I.I., Smith, P., Graves, P.J. & Linton, M. Chronic disease in childhood: a study of family reactions. British Journal of Medical Education, 1966, 3 (66).

Furman, R.A. The child's reaction to death in the family. In B. Schoenberg, A. Carr, D. Peretz, A. Kutscher (Eds.), Loss and grief: psychological management in medical practice. New York and London: Columbia University Press, 1970, pp. 71-85.

Futterman, E.H., & Hoffman. Crisis and adaptation in the families of fatally ill children. In E.J. Anthony and C. Koupernik (Eds.), The child and his family (Vol. II). New York: John Wiley and Sons, 1973, pp. 127-143.

Gath, A. The mental health of siblings of congenitally abnormal children. J. Child. Psychol. Psychiatry, 1972, 13, 211.

Gayton, W.F., Friedman, S.B., Tavormina, J.F., & Tucker, F. Children with cystic fibrosis: I. psychological test findings of patients, siblings and parents. Pediatrics, June 1977, 59 (6), 888-894.

Gogan, J.L., Koocher, G.P., Foster, D.J. & O'Malley, J.E. The impact of childhood cancer on siblings. Health and Social Work, February 1977, 2 (1), 42-57.

Gourevitch, M. A survey of family reactions to disease and death in a family member. In E.J. Anthony and C. Koupernik (Eds.), The child and his family (Vol. II). New York: John Wiley and Sons, 1973, 21-27.

Gyulay, J. Care of the dying child. Nursing Clinics of North America, March 1976, 11 (1), 95-107.

Holmes, T.H. & Rahe, R.H. The social readjustment rating scale. Journal of Psychomatic Research, 1967, 11, 213.

Kaplan, D.M., Grobstein, R. & Smith, A. Predicting the impact of severe illness in families. Health and Social Work, August 1976, 1 (3), 72-81.

Iles, J.P. Children with cancer: healthy siblings' perceptions during the illness experience. Cancer Nursing, October 1979, 371-377.

Lavigne, J.K. & Ryan, M. Psychologic adjustment of siblings of children with chronic illness. Pediatrics, April 1979, 63 (4), 616-627.

Lascari, A.D. The dying child and the family. The Journal of Family Practice, 1978, 6 (6), 1279-1286.

Lawson, B. Chronic illness in the school-aged child: effects on the total family. American Journal of Maternal Child Nursing, January/February 1977, 49-56.

Maddison, D. & Raphael, B. Social and psychological consequences of chronic disease in childhood. Medical Journal of Australia, 1971, 2, 1265-1270.

Maddison, D. & Raphael, B. The family of the dying patient. In B. Schoenberg, A. Carr, D. Peretz, A. Kutscher (Eds.), Psychological aspects of terminal care. New York and London: Columbia Press, 1972, pp.

Mattsson, A. Long term physical illness in childhood: a challenge to psychosocial adaptation. Pediatrics, 1972, 50 (5), 801-811.

Meyerowitz, J.H. & Kaplan, H.B. Familial responses to stress: the case of cystic fibrosis. Social Science and Medicine, 1967, o, 249-266.

Minde, K. The impact of social, psychological and physical illness on the child and his family. Canada's Mental Health, March 1978, 26 (1), 17-20.

Morrissey, J.R. Death anxiety in children with a fatal illness. In H. Parod (Ed.), Crisis intervention. New York: Family Ser. Assoc. of Am., 1965.

Nagy, M. The child's theories concerning death. The Journal of Genetic Psychology, 1978, 73, 3-27.

Natterson, J.M., & Knudson, A.G. Observations concerning fear of death in fatally ill children and their mothers. Psychosomatic Medicine, 1960, 22, 456-465.

Prugh, D.G., Staub, E.M., Sands, H.H., Kirschbaurn, R.M., & Lenihan, E.A. A study of the emotional reactions of children to hospitalization and illness. American Journal of Orthopsychiatry, 1953, 23, 70-106.

Roy, C. Sr. Adaptations: Basis for nursing practice. Nursing Outlook, April 1971, 255-258.

Richmond, J.B., & Waisman, H.A. Physiologic aspects of management of children with malignant diseases. A.M.A. American Journal of Diseases in Children, 1955, 89, 42-47.

Sarason, S.B., Lighthall, F.F., Davidson, K.S., Waite, R.R. & Ruebush, B.K. Anxiety in elementary school children (Science Editions). New York: John Wiley and Sons, Inc., 1960.

Spinetta, J.J., Rigler, D., & Karon, M. Anxiety in the dying child. Pediatrics, December 1973, 52 (6), 841-845.

Spinetta, J.J., & Maloney, L.J. Death anxiety in the outpatient leukemic child. Pediatrics, December 1975, 56 (6), 1034-1037.

Steinhauer, P.D., Mushin, D., & Raie-Grant, Q. Psychological aspects of chronic illness. Pediatric Clinics of North America, November 1974, 21 (4).

Tew, B., & Lawrence, K.M. Mothers, brothers, and sisters of patients with Spina Bifida. Developmental Medicine and Neurology, 1973, 15 (6), 69.

Travis, G. Chronic illness in children: Its impact on child and family. Stanford, California: Stanford University Press, 1976.

Turk, J. Impact of cystic fibrosis on family functioning. Pediatrics, July 1964, 34, 67-71.

van Eys, J. The outlook for the child with cancer. Journal of School Health, March 1977, 47 (3), 165-169.

Waechter, E.H. Death anxiety in children with fatal illness. Unpublished doctoral dissertation. Stanford University, 1968.

Waechter, E.H. Children's awareness of fatal illness. American Journal of Nursing, 1971, 71 (6), 1168-1172.

Wiener, J.M. Reaction of the family to the fatal illness of a child. In B. Schoenberg, A.Carr, D. Peretz, & A. Kutscher (Eds.), Loss and grief: Psychological management. New York and London: Columbia University Press, 1970, pp. 87-101.

Winer, B.J. Statistical principles in experimental design (2nd ed.). New York: McGraw-Hill Book Company, 1971, p. 9.